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ABSTRACT

This volume contains materials presented at a one-day conference on family support for the care of older adults. Checklists and guides are included on evaluating and meeting the needs of older persons. A discussion guide for those taking care of older parents covers ways in which to support the older persons and the entire family. Several resources are listed. A handbook by the American Association of Retired Persons on caring for the older person in one's home is also presented and discussed. Three position papers are included: (1) "Caring for Your Aging Loved Ones: A Three Agency Community Service" (David Turner and Alberta W. Blue); (2) "Feelings of Burden Among Adult Children Caring for Aged Parents: Results of a Pilot Study" (Clifton E. Barber); and (3) "The Alzheimer Spouse: Caring and Coping" (Marjorie P. Westergard). (CB)

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PERSPECTIVES ON AGING

Family Support in Elder Care:

Designing Practical Solutions for Recurring Problems

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SP 027 464

HOSTED AT: BRIGHAM YOUNG UNIVERSITY

March 13, 1986

DIRECTED BY: DR. HOWARD R. GRAY

PERSPECTIVES ON AGING

Family Support in Elder Care:

Designing Practical Solutions for
Recurring Problems

PROGRAM CONTENT:

List of Presenters

Presentation Notes

Evaluating Older Persons Needs

My Mother, My Father - Caring for Aging Parents Discussion Guide

Handbook Hints About Care in the Home

Position Papers:

1. Caring for Your Aging Loved Ones: A Three Agency Community Service

2. Feelings of Burden Among Adult Children Caring for Aged Parents

3. The Alzheimer Spouse: Caring and Coping

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PRESENTATION NOTES

WORKSHOP #2
Understanding Legal Questions and Concerns of Caregivers

Presenter: Mr. Kenneth E. Bresin, Attorney at Law, Utah Legal Services, Senior Citizens Law Project

"Individuals ought to retain control of their property and finances for as long as possible. However, numerous ways exist to smooth the transference of personal autonomy and ownership of property in the event of an incapacitating illness or death; such transfers may take place only in the event of an incapacitating illness or death. Without sufficient legal guidance, I may transfer property to myself and one of my children as a means to assure that such property is distributed amongst all of my children only to find that the property is being taken from me because of something my co-owner child did. In other words, 'loss avoidance' may be more important than probate avoidance. And a frank discussion with one's family members, coupled with a simple legal device, prior to the onset of a debilitating illness such as Alzheimer's disease, will usually prevent the need for a guardianship proceeding in District Court."

Other workshop presentations were videotaped; contact:

Resource Center
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Provo, UT 84602

Table 1

EVALUATING THE NEEDS OF AN OLDER PERSON

NEEDS	NO NEED	NEED BEING MET	NEED EXISTS BUT NOT CURRENTLY MET	COMMENTS
Physical — Occasional Health Activities				
Diagnosis or help for:				
Vision problems (with glasses)				
Hearing problems (with hearing aid)				
Speech evaluation or therapy				
Diagnosis or treatment for physical complaints				
Psychosocial				
Communication problems				
Meaningful activities on a daily basis				
Extreme anxiety and worries				
Sleep problems				
Decreased interest in self-care				
Prolonged grief (grief lasting more than six months may indicate depression which is a serious condition)				
Persisting guilt feelings and regrets				
"Acting out", combative or self-destructive behavior				
Memory problems				
Loneliness				
Paranoid behaviors				
Confusion and disorientation				
Touch and sexual identity				
Social contact and/or support				
Privacy				
Humor and fun				

Source: Ebenezer Center for Aging, Minneapolis, Minnesota

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Table 2

EVALUATING RESOURCES FOR CARESHARING

Social Resources	YES	NO	NOTES
• Is there a spouse or someone living with the older person?	____	____	
• Is there more than one family member who is willing and able to be involved in the care of the older person?	____	____	
• Are there friends or neighbors who stop by to visit the older person on a regular basis?	____	____	
• Are there friends or neighbors who do errands or other favors for the older person?	____	____	
• Are there neighbors — teens or adults — who could be hired to do certain chores or errands?	____	____	
• Has the older person currently or in the past been a member of a church, fraternal or other organization that will perform services of any kind for its older members or former members?	____	____	
Personal Resources			
• Is the older person able to do some housekeeping and meal preparation independently?	____	____	
• Can the older person do grooming independently?	____	____	
• Is the older person safe and content if left alone for periods of time?	____	____	
• Is the older person agreeable and cooperative when relating to helpers?	____	____	
• Can the older person see, hear and communicate?	____	____	
• Is the older person alert and able to remember?	____	____	
• Can the older person transfer and move around independently?	____	____	

Source: Ebenezer Center for Aging, Minneapolis, Minnesota.

(Continued)

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HOW ARE YOU DOING AS A CARING RELATIVE?

Directions: If the statement is mostly true for you, write true in the space at the left. If the statement is mostly false for you, write false in the space at the left.

_____ 1. I have been so involved with the job of caring for my older relative that I have not taken time off from that responsibility for several months.

_____ 2. I provide almost all of the care and support for my older relative because no one else really understands and cares the way I do.

_____ 3. I encourage my older relative to be independent and do as many things as possible for him/herself.

_____ 4. I occasionally become angry or impatient with my older relative.

_____ 5. I am "on call" 24 hours a day and I try to respond quickly to all the requests and needs of my older relative.

_____ 6. I know about the organizations in my community that provide services and nursing home care to the elderly, and I know where to call to obtain these services if they are needed.

_____ 7. I can do a good job of caring for an elderly person without having any special training, reading, or education about aging and care of the elderly.

_____ 8. I consider a nursing home as a last resort for my older relative.

_____ 9. I have made plans for providing care if I become disabled or if my older relative begins to need more care than I can provide.

_____ 10. I would never leave a disoriented or confused older person alone or unattended.

_____ 11. I am the primary one who cares for my older relative because there is no one else who would do it or could do it as well.

_____ 12. I have friends and relatives who give me support by helping, listening to my problems, or just having fun with me.

_____ 13. I have promised my older relative that I would "never put him/her into a nursing home."

_____ 14. One way I help my older relative is by taking the burden of decision making.

_____ 15. At least once a week, I do something for fun.

_____ 16. There are some activities that my older relative and I can do to have fun together.

_____ 17. I provide almost all of the care for my older relative because I do not want to impose on my family and friends.

_____ 18. I have contact with my older relative on a regular basis, check to make sure that the environment is safe, and that the older person is eating well and receiving adequate health care.

_____ 19. I think that it is almost always best for an older person to live in the same home with the relative who is providing care.

_____ 20. I would not accept money or gifts for the things I do because I provide care and assistance for my older relative out of a sense of love and responsibility.

_____ 21. I have been taught to use my body correctly when I lift or transfer my older relative.

_____ 22. I am very knowledgeable about the medications my older relative takes. I feel it is my responsibility to understand the complications that can arise from medications.

_____ 23. I know how to prevent skin problems for the elderly and how to check for signs of skin breakdown.

_____ 24. Older persons often have problems with stability and imbalance when they are walking, so I encourage my older relative to wear shoes that are comfortable, supportive and secure.

_____ 25. Since I began being responsible for the care of my older relative, I have experienced one or more of the following: a change in weight of more than 10 lbs. (this means either weight loss or weight gain); sleeping difficulties; increased use of medications (including aspirin, sleeping pills, and tranquilizers); increased use of alcohol or tobacco.

_____ 26. I have checked my older relative's home for safety hazards (this includes unsturdy or low furniture, clutter, throw rugs, stairways without handrails, and slippery floors) that could cause falls.

_____ 27. I understand that tight fitting clothing (such as shoes, corsets, and nylon knee high stockings) constrict blood flow and can lead to health problems.

_____ 28. At this point, the best thing I can do is treat my older relative as a child.

Source: Ebenezer Center for Aging, Minneapolis, Minnesota

DISCUSSION GUIDE

HOW ARE YOU DOING AS A CARING RELATIVE?

Compare the response to the question with your own. Then read the discussion paragraph to see why the response is preferred.

False 1. I have been so involved with the job of caring for my older relative that I have not taken time off from that responsibility for several months.

Caring relatives can carry out their responsibilities most effectively when they are not feeling stressed, emotionally exhausted, or physically tired. All people need some personal time for privacy and relaxation. Caring relatives need "time off" and the older individuals may also need some time with different people.

False 2. I provide almost all of the care and support for my older relative because no one else really understands and cares the way I do.

Sometimes, there is one individual who assumes primary responsibility or whom older family members respond to most readily. It is unwise and impractical for older people to be dependent on one person for their security and survival. It is important not to foster dependence on one caring relative. As a caring relative, you must actively seek partners in the responsibility of caring and allow older people the security of having a number of persons on whom they can rely.

True 3. I encourage my older relative to be independent and do as many things as possible for him/herself.

Frail or handicapped people usually stay healthier and feel better about themselves when they are allowed or encouraged to take care of their own needs as much as possible. Caregivers should do only the things that older persons cannot do for themselves. For example, if a man is able to dress himself on top, but not on the bottom, the caregiver should help only with the bottom.

True 4. I occasionally become angry or impatient with my older relative.

Caring relatives are human and caring for older people can be stressful. It is normal to become angry and frustrated at times. It is also important to plan constructive ways to express the anger and frustration. For example, you might talk about it to a friend or take a walk. If you feel angry or raise your voice often (say 50% of the time), you may have a problem and you should reevaluate the situation and consider getting additional support or professional help.

False 5. I am "on call" 24 hours a day and I try to respond quickly to all the requests and needs of my older relative.

Caring relatives may need to be "on call" 24 hours a day, but this does not mean they must respond immediately to all needs and requests. There are times when caring persons must think of their own limitations, evaluate requests and ask the older people to wait or do without.

True 6. I know about the organizations in my community that provide services and nursing home care to the elderly, and I know where to call to obtain these services if they are needed.

Caring relatives do not necessarily have to provide actual "hands on" care for older people. In fact, sometimes it may be better for a person with training to do a particular job. Your role may be to find the help that is needed. You may need to spend a lot of time on the phone to learn about services and find help for yourself and your older relative. This can be a difficult and frustrating job, but in the long run, it will usually be worth the effort.

False 7. I can do a good job of caring for an elderly person without having any special training, reading, or education about aging and care of the elderly.

Caring relatives can be more effective and more comfortable in their roles if they understand the illness or disability experienced by the older person and if they know some basic techniques for adapting the environment and giving hands-on care. People can get such training and education in various ways, including reading, formal classes and consultation with various professionals including physicians, home care nurses, and social workers.

Source: Ebenezer Center for Aging, Minneapolis, Minnesota

False 8. I consider a nursing home as a last resort for my older relative.

Many caring relatives and many older people do believe nursing homes are a last resort. However, there are situations in which moving to a nursing home can be the best plan for both the older person and the caring relative. The home can offer round-the-clock care and excellent programs of therapy, recreation and health care that would not be available in a person's own home. In a nursing home, the stress of caregiving is shared by a number of staff. Caring relatives and older people often say they experience renewed closeness and more meaningful social interaction when the older people move to the safety and professional care of the nursing home.

True 9. I have made plans for providing care if I become disabled or if my older relative begins to need more care than I can provide.

Caring relatives should think about the circumstances under which the caring relationship will need to be changed. There should be a back-up plan to accomodate the changing health needs of the older person. Everyone should know who will help in emergencies and who will provide care if the caring relative cannot act in that role.

False 10. I would never leave a disoriented or confused older person alone or unattended.

Disoriented persons should not be left unattended in situations they cannot manage. However, if disoriented people are able to be safe and feel secure, leaving them alone sometimes may enhance their feelings of privacy and independence and also allow the caring relative to have some freedom. For example, a woman whose main difficulty was with the oven could be left alone if the gas was shut off.

True 11. I am the primary one who cares for my older relative because there is no one else who would do it or could do it as well.

There are different reasons for one person in a family to become the primary caring relative. Ideally, the choice should be made through a process of open discussion and consideration of the needs, resources, and preferences of all of the parties involved. Also, in some cases, it is appropriate for several family members to share some of the responsibilities. Often, people become involved because they respond to a crisis, then they never seem to change that role. When people feel they have gone through an inequitable process, or when they feel other family members "stole" the caring role from them, family problems can occur.

True 12. I have friends and relatives who give me support by helping, listening to my problems, or just having fun with me.

Caring for an older person can be a lonely and stressful experience. A strong support group can give the caring relative renewed energy and strength. The caring relative who can find no time to spend with supportive friends and relatives is more likely to have difficulty sustaining their efforts over time.

False 13. I have promised my older relative that I would "never put him/her into a nursing home."

Many caring relatives have made this promise and have been unable to keep it. It is not wise or kind to make a promise you may not be able to keep. Even if you are able to give care now, things may change. The older person may grow to need special nursing care that you cannot possibly provide at home, or you may develop problems that prevent you from continuing your caring role.

False 14. One way I help my older relative is by taking the burden of decision making.

It is important for all people to feel they have some control and choice in their lives. Even a person who is ill or disabled or forgetful can assist in making at least some decisions.

True 15. At least once a week, I do something for fun.

A person who regularly has some fun and relaxation will have more to give the older relative.

True 16. There are some activities that my older relative and I can do to have fun together.

Older people need to have fun even if they are frail or confused. Having fun with caring relatives can also make older people feel better about themselves and less like a burden to the caring relatives.

False 17. I provide almost all of the care for my older relative because I do not want to impose on my family and friends.

Source: Ebenezer Center for Aging, Minneapolis, Minnesota

See discussion for #11 and #12. It is not unusual for women who are caring relatives to take most of the burden themselves and avoid asking the help of their children or spouses. While it is admirable to want to do this, it is also very stressful, time consuming and tiring. Sometimes, families and marriages will be better off if caring for the older person is shared among family members.

True 18. I have contact with my older relative on a regular basis, check to make sure that the environment is safe, and that the older person is eating well and receiving adequate health care.

Older people do not always ask for or may even reject help when they need it. When people are sick or very frail, a caring relative should have regular contact and watch for signs of problems. When older people cannot take care of their basic needs themselves, they need someone to intercede and oversee their care. The caring relative may provide actual care or obtain and supervise services.

False 19. I think that it is almost always best for an older person to live in the same home with the relative who is providing care.

Sometimes this is true. On the other hand, it is common for older people and their caring relatives to live in different homes with the caring relatives overseeing the care and ensuring that the older people's needs are met. For some older people, it is important that they can stay in the familiar surroundings of their own homes and experience privacy and independence. For some caring relatives and their families, it would be a hardship to have the older person living with them in their home. There is no rule to follow; each situation is different.

False 20. I would not accept money or gifts for the things I do because I provide care and assistance for my older relative out of a sense of love and responsibility.

Caring relatives usually provide care or assistance because of love and commitment and they prefer not to receive gifts or money for their service. They should be aware of the fact that older people may want to repay or show thanks for the assistance they receive. Also, caring relatives may have some high costs for such things as mileage, child care, and purchase of groceries and medicine. They should carefully document their costs of caring for the individual and when possible, some or all of those costs should be reimbursed. It is very important to document amounts of money that change hands and dates on which this occurs. If you are managing another individual's financial affairs, it is wise to seek legal advice to insure proper documentation.

True 21. I have been taught to use my body correctly when I lift or transfer my older relative.

A person who lifts or assists others with walking and transferring is at high risk of injuring him/herself (particularly back injuries) if proper techniques and equipment are not used. When proper transferring techniques are used, the older person can be transferred more safely and comfortably.

True 22. I am very knowledgeable about the medications my older relative takes. I feel it is my responsibility to understand the complications that can arise from medications.

It is beneficial for a caring relative to have some knowledge of the medications taken by the older person because there may be problems with such things as side effects and noncompliance with the physician's orders. You can learn about medications by reading and by talking to your physician and pharmacist.

True 23. I know how to prevent skin problems for the elderly and how to check for signs of skin breakdown.

Skin problems are common among frail elderly, particularly those who are not physically active. Preventing skin problems and detecting them right away can be important to the health and comfort of the older person.

True 24. Older persons often have problems with stability and imbalance when they are walking, so I encourage my older relative to wear shoes that are comfortable, supportive and secure.

Older soft shoes or slippers may feel more comfortable to an older person, but such shoes also increase the risk of falls.

False 25. Since I began being responsible for the care of my older relative, I have experienced one or more of the following: a change in weight of more than 10 lbs. (this means either weight loss or weight gain); sleeping difficulties; increased use of medications (including aspirin, sleeping

Source: Ebenezer Center for Aging, Minneapolis, Minnesota

pills, and tranquilizers); increased use of alcohol or tobacco.

These can all be symptoms of stress and/or depression. If you have had these problems, you should seek professional help or advice.

True 26. I have checked my older relative's home for safety hazards (this includes unsturdy or low furniture, clutter, throw rugs, stairways without handrails, and slippery floors) that could cause falls.

Falls are a serious problem for older people. The environment can be adapted in many ways to improve safety for the older person.

True 27. I understand that tight fitting clothing (such as shoes, corsets, and nylon knee high stockings) constrict blood flow and can lead to health problems.

Circulation is decreased in the elderly and constricting garments can increase swelling and skin problems.

False 28. At this point, the best thing I can do is treat my older relative as a child.

When an older person becomes frail and/or forgetful and requires a great deal of assistance, family members sometimes think they are becoming childlike and the family begins to take a parental role. This is called "role reversal". When an older adult is treated as a child, it undermines that person's self-esteem. It is important for a caring relative to provide the needed care and at the same time, preserve the adult status and self-esteem of the older person.

Source: Ebenezer Center for Aging, Minneapolis, Minnesota

TERRA NOVA FILMS

Discussion Guide

for the film

My Mother, My Father

(Caring for Aging Parents)

BEST COPY AVAILABLE

Who Should See This Film?

- Adult Children of Frail Parents
- Caregiver Support Groups
- Caregiver Support Group Leaders
- Health Care Professionals, including:
  - Adult Day Care Personnel
  - Nursing Home Personnel
  - Respite Care Providers
  - Home Health Care Workers
  - Hospital Personnel, especially social workers, nurses and discharge planners
- Clergy
- Church groups
- Community groups
- Senior Center Staff
- Mental Health Professionals
- Family Counselors
- Social Workers
- Gerontology Students
- Medical and Nursing students

Some Facts on Aging and Caregiving

- For every person now in an institution, at least two with similar disabilities are being cared for in the community. One-third of these need constant rather than intermittent care. Caregiving concerns like those shown in the film are increasing as the numbers of elderly continue to increase.

- Persons 65 and older comprise 11% of the total population--24 million persons (compared with 3.1 million at the turn of the century.) By the year 2030, the total population will grow 40%. The elderly population will almost double. The population over 85 will almost triple!

- It is a myth that families abandon their elders. A recent study revealed that more than half of the older persons surveyed saw at least one of their children on the day of the interview or the day before, that three-quarters of them had seen their children within a week, and that only 10% had not seen even one of the children within a month preceding the interview.

- Family, friends, neighbors, and other non-professionals are the care-providers most preferred by the elderly. In general, a flow of give and take exists between older and younger relatives throughout an individual's lifetime. But as elderly family members become more dependent financially or socially, they may receive more of some kinds of assistance than they give. Families provide many kinds of direct physical assistance, as well as financial assistance and emotional support.

Some Thoughts on Family Caregiving

Although many families wish to provide care for elderly members, their ability to do so is influenced by many trends in contemporary life.

Among these are:

- Increased employment of women, the traditional caregivers
- Lowered birth rates (fewer children to provide care)
- Increased divorced and single-parent families
- Increased longevity (both parents and grandparents may need care)
- Increased mobility (children may live across country)
- Lack of community support services for home-bound elderly

Various supportive services and resources for families caring for an older person are available. Reputable health care agencies and institutions in the community will readily provide this information to caregiver families who seek it.

In addition, many hospitals, colleges and churches now provide (or will provide, if asked) educational programs and caregiver support groups for families caring for a frail older person.

These kinds of supportive services help a family to continue to care for an elder, and thus delay or prevent placement in a long-term care facility.

However, nursing home placement may be the long-term care plan of choice for some elderly and their families. When safety, loneliness, isolation and health needs make home a less desirable place, it may be a relief to choose a nursing home or a retirement home over home care. Cost of services for extensive care from community agencies may also be a factor in the decision for placement.

Some Ways to Use the Film, "MY MOTHER, MY FATHER"

One 2-4 Hour Session:

A brief session starting with the film and followed by discussion in small groups of 4-6 , using a professional from the community or a seasoned caregiver to facilitate each small group. These facilitators may have been included in the planning and promotion of the program and may wish to preview the film and have copies of this discussion guide ahead of time. The program coordinator may wish to wind up the program with brief reports from each group, sharing highlights of the group's experiences.

A Day Long Workshop:

In addition to the above, you may wish to begin the day with an exercise in which paired participants share 1) their own caregiving experiences and 2) what they expect from the workshop. This pair could then choose another pair after the film to form a group of four for the post-film discussion. The discussion could continue until the lunch break.

After lunch you could present a panel of service providers from your community (or program directors from your own agency) who could talk about the services available to home-bound older persons and their families.

You may want to offer a number of mini-sessions where some of the following topics could be presented and discussed in more detail:

- Myths and Stereotypes of Aging
- When is Guardianship an Option?
- Deciding Who Does What--The Family Conference
- Feelings of Caregivers
- Managing Difficult Behaviors
- The Normal Aging Process
- Accessing and Utilizing Community Resources
- How to Start a Self-Help Support Group for Caregivers
- Skills and Conditions for Home Care
- Alternative Living Arrangements
- Taking Care of the Caregiver
- Helping the Elder Cope with Grief and Loss
- Death and Dying and Home Care
- Time Management for the Caregiver
- Communication with Someone Who Has a Dementing Illness
- The Finances of Caregiving

6-8 Sessions:

You may wish to plan a series of sessions for caregivers choosing from the topics previously listed. Some people may prefer to use the film in four segments, showing one family each week for four weeks, discussing the issues and concerns of that family as they apply to the caregiver's own situation. These groups of participants may choose to spin off from this experience into a self-help, mutual support and problem solving group, inviting professionals in to lecture as skills and information are identified and needed.

Considerations For Facilitating Your Discussion Group

The adult participant has experiences and information of value to others in the group. This experience can be organized around discussion points or topics. Remember that adults as learners:

- Are self-directing
- Are responsible for themselves and their learning
- Learn more if they participate actively/share
- Have much to contribute
- Apply learning to current life situations
- Require practical application/results

There are a number of facilitator qualities and skills which help to create a positive climate for risking and sharing. Warmth, sincerity, patience, understanding, flexibility and perseverence are all human qualities which help to create a climate of openness and trust. Skills in interpersonal communication, listening, and empathizing are also important. In creating a positive learning climate, a facilitator should do the following:

- Provide a non-threatening atmosphere which encourages participants to express their ideas, opinions, feelings and experiences.
- Arrange to meet in a comfortable setting where there are a minimum of outside noises or distractions.
- Design discussion groups of 4-6 participants. It is easier to speak in a smaller group.
- Sit in a circle so everyone can see and hear each other.
- Ask questions to stimulate discussion.
- Encourage sharing of resources, ideas, feelings and solutions.
- Challenge without attacking self-worth, confidence or integrity.
- Provide positive and constructive feedback.
- Allow for clarification and discussion of issues.
- Don't be afraid of silence! Participants need time to think.
- Emphasize that conclusion or resolution need not always be reached. There is no right answer!
- Promote mutual support and networking.

About Terra Nova Films

Terra Nova Films is a not-for-profit company specializing in the production and distribution of films that explore social and personal issues.

Since its inception in 1979 by its present director, James Vanden Bosch, the hallmarks of our films have been to show the dignity of all people, challenge stereotypes and encourage caring attitudes.

Other films that Terra Nova has produced include:

BECAUSE SOMEBODY CARES, a film about the warm exchange of friendship between volunteer friendly visitors and isolated older persons. **Winner of the 1981 National Mental Health Association Film Festival's *Best in Show Award.***

TAKE A STAND, a film about victim assitance for older persons who have been victims of crime. This film shows the advantage of asserting one's rights in court. **Winner of the 1983 American Film Festival's *Red Ribbon Award.***

WE ARE THE CHURCH TOGETHER, a film about special religious education for persons with mental handicaps.

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INFORMATION
ON
HOME HEALTH
SERVICES:

A HANDBOOK ABOUT CARE IN THE HOME

A Publication of
Health Advocacy Services
Program Department

AMERICAN
ASSOCIATION
OF RETIRED
PERSONS

SERVICES FRIENDS AND COMMUNITY ORGANIZATIONS CAN PROVIDE

Many services, some of which are low cost or free, are available in some communities to assist persons confined to their homes, including:

■ **Day Care Programs** usually provide medical services as well as social and recreational programs. The people who benefit most from day care activities are those who live alone, or whose family and friends work during the day. Day care programs usually operate five days a week, 9 am to 5 pm, and are often sponsored by religious, fraternal, or neighborhood organizations, or a unit of a hospital or clinic.

The medical help available is usually limited to administering medicines or minor medical treatment supervised by a registered nurse. Occasionally, speech or hearing therapy, physical therapy, or occupational therapy is available, but participants are expected to be mobile.

The cost is usually about $10 to $30 per day, but some programs operate on a sliding scale which adjusts payment to income. Community organizations frequently sponsor individuals who cannot afford to attend. Medicaid is probably the major source of payment for most people, and must approve each person's eligibility.

Home health care nurses may recommend participation in adult day care programs when a patient completes home care treatment and is physically able to leave the home.

■ **Friendly Visitor Program** is similar to the telephone reassurance program, except that someone visits the patient on a regular basis rather than simply calling on the telephone. The volunteer's visit is usually scheduled for a predetermined, regular time, usually once or twice per week.

■ **Hospice** represents a philosophy of care which provides physical, emotional and sometimes spiritual help to terminally ill persons and their families. With hospice support, a dying person may be able to remain at home. Many hospice programs are sponsored by home health agencies which use the same health professionals to provide home health care and hospice care.

Hospice care attempts to:

- decrease the pain and discomfort of the patient by controlling the symptoms of the illness.

- make life as full and meaningful as possible until death.
- provide support for the patient, the family, and the friends.

Hospice care is usually available 24 hours a day, seven days a week. When a physician orders hospice care and it is provided by a certified home health agency, costs may be partially covered by Medicare or Medicaid.

- **Meals on Wheels** provides hot, nutritious home-delivered meals once, and sometimes twice a day, five days a week, to persons who are unable to cook for themselves. There is usually a sliding fee for meals, determined by each individual's ability to pay.
- **Respite Care** offers support so family or friends can take a break from the demands of continual home care. When a family or friends care for a person in their home, they may need temporary replacement support when they are unable to provide the care that is needed, i.e., during a vacation, an emergency or working hours. Respite care offers this support.

Respite care usually includes nursing care, chore services, and meals, and can be provided in most cases up to 24 hours a day. A respite care staff person or volunteer may come to the home and stay with the person when family or friends must be away. Or, a respite center may have an in-house facility where the individual can choose to stay while the family is away. The cost varies according to the amount of support needed.

Information about these services can be obtained from home health agencies, public health departments, churches, day care centers, senior citizen centers, social service departments, Area Agencies on Aging, and civic clubs.

- **Telephone Reassurance** is a free service provided by church, civic or fraternal organizations and sometimes by home health agency volunteers. This service provides daily contact for persons who live alone, or who are alone during the day and worried abut their health or safety. The client calls in every day at a pre-determined time, or a volunteer will call the client. If a client doesn't call in, or if calls by a volunteer aren't answered, the neighbors or police are alerted to check on the client.
- **Transportation programs** provide transportation to needed services such as physician visits and grocery

'Churches, civic or fraternal organizations, and sometimes home health agency volunteers provide daily contact for persons who live alone, or are alone during the day.'

'The patient and family should discuss the care received and decide if it is meeting the patient's health needs.'

shopping for individuals who are unable to transport themselves. Transportation may be by volunteer drivers or by bus, taxi, or specially-equipped van service.

HOW CAN FAMILIES AND FRIENDS HELP?

There are many ways for relatives or friends to support sick and homebound patients, with or without the help of a home health agency. This support can be both physical and emotional. A person often feels more comfortable with family help than with a stranger in the home; close relatives or friends can provide this feeling of intimacy and comfort.

Family members or friends can also reduce the costs that would otherwise be incurred by helping with the following tasks:

- personal hygiene (bathing, toilet)
- changing bed linens
- house cleaning
- preparing meals
- grocery shopping
- washing clothes
- helping the patient in and out of bed
- assisting with medications

Family members or friends uncomfortable or afraid to care for a person's needs in the home might benefit from health training instruction available through local Red Cross chapters, home health agency nurses, or health department visiting nurses.

Families who are considering, or providing home care for a person, and want more detailed information on what they can do, should read *Home Care for the Elderly* by J. Trocchio, printed by CBI Publishing Co. in Boston, (1981). The book provides both clear direction on basic care needs that family members can provide, as well as explaining what broad needs and issues are involved in caring for someone at home. The book can be very helpful to families who want to help.

HOW DOES HOME HEALTH CARE COMPARE WITH INSTITUTIONAL CARE?

A need for institutional care usually arises when a person has a "chronic" ailment, a condition of long duration which can recur frequently.

Institutionalization may be necessary when the condition is so severe or debilitating that the person is unable to care for himself or herself or friends and relatives are either not available or unable to help. A chronic illness, however, does not

EVALUATING THE QUALITY OF HOME HEALTH SERVICES

necessarily require institutional care.

For several years, the government has issued reports on the effectiveness of home health care. A study by the General Accounting Office indicated that for most persons over 65 years of age, restorative or convalescent care can be provided in the home, for less than the same services provided by an institution.* Some of these savings are attributed to the support provided by a person's family or friends.

If problems occur with the selected agency, local consumer groups, such as the Better Business Bureau, or local Consumer Affairs office, should be contacted. Also, if the agency is a member of a national group, the association should be notified. A listing of the national groups is included in the Resource section.

* U.S. Congress. Report of the Comptroller General of the United States. *Home Health — The Need for a National Policy to Better Provide for the Elderly.* Washington, D.C. Government Printing Office, 1977.

In some communities there may be only one home health care agency, but when several choices are available, the patient or family should try to make an objective evaluation of which agency is most suitable for the homebound person.

After home health care services begin, this evaluation should continue. The patient and family should discuss the care received and decide if it is adequately meeting the patient's health needs.

The checklists at the back of this booklet can be used to compare the type of services offered by several different agencies. By answering the questions and filling in one column for each agency, it is easier to determine if an agency has met quality standards and can provide the services needed by the patient. Space is also provided for cost-comparisons between the services offered by different agencies. The final section of Checklist B is to be used after service begins, to assess satisfaction in the services provided.

HOW TO ARRANGE A HOMEBOUND PERSON'S ENVIRONMENT

There are many simple, inexpensive ways to make a home safer and more comfortable for a homebound person. Most of the equipment that may be needed to make these home adjustments can be bought at a hardware store; other adjustments can be made at no cost.

- If a patient is confined to bed, make sure a TV, radio and telephone are accessible, as well as books and magazines, a reading lamp, call bell, water pitcher and glass, clock, and calendar.
- Avoid stairs. Use a first floor room even if it means converting another room into a bedroom. If steps can't be avoided, try to install a ramp.
- A colorful room with large windows and a nice view is pleasant for a bedridden patient.
- The bathroom should be on the same floor, close to the person's room.
- Grab-bars or hand-rails can be purchased and installed in hallways and in bathrooms next to the toilet and in the shower. Bars make walking and getting up and down easier and safer. (Cost @ $5 - $25)
- Remove all elevated door sills or avoid them with a ramp.
- Shag carpets, slick floors and scatter rugs should be eliminated because of the danger of falls.
- Make sure lighting is bright and adequate in the person's room and hallways.
- In case of fire, prepare a plan of escape for the bedridden person.
- If a person is hard of hearing, install an amplifier on the phone and turn the phone buzzer on loud.
- Adhesive strips can be applied to the bathtub to prevent slipping. (Cost @ $2)
- A bench can be placed in the bathtub for easy and safe access. (Cost @ $5 - $70, depending on the style and material.)
- Wrist-straps can be made for walkers and canes to prevent dropping them. Straps can be made of tape, cloth or rope.
- Enlarge handles of knives, forks and spoons to enable weak or arthritic patients to hold the utensils with less effort and more control. Foam rubber, velcro, cloth, garden hose, etc., can be used.
- Change door handles to a lever type rather than a knob to assist weak or arthritic patients. (Cost @ $10)
- Plastic mattress covers protect a bed if a person eats or bathes in bed or is

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incontinent. Add a mattress pad over the plastic for comfort and to avoid slipping. Since these pads must be changed immediately when soiled, several will be needed.

At more expense, the following equipment can be obtained to make a homebound person more comfortable. This equipment can be purchased or rented through a hospital, surgical supply store, or pharmacy. Depending upon a person's medical condition, Medicare and Medicaid may reimburse for some of these items.

- Buy or rent an electric or manual hospital bed to help the patient sit up and get in and out of bed. (Cost $1,000 for a new electrical hospital bed; rental costs vary.)
- Purchase side-rails for a regular bed if a person needs help getting in and out of bed or something to hold when turning over in bed.
- A water bed, air mattress, or foam padding can be purchased for a person confined to bed to reduce the chance of bedsores. (Costs vary)
- A trapeze can be purchased and installed above a bed so the patient can grab it to move around in bed. (Cost $40 - $125)
- An overbed table like those used in hospitals facilitates eating, reading, and writing in bed. (Cost $10 - $175)
- An easy lift chair is a mechanical or electric chair whose seat lifts up to make getting in and out of a chair easier.
- A standard hospital type wheelchair costs $250 - $400.
- Second-hand chairs may be available from the Red Cross or Salvation Army.
- A walker increases safety and ease in walking alone. (Cost $50 - $60)

'Simple, inexpensive ways can make a home safer and more comfortable for a homebound person.'

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DEFINITIONS

AMBULATORY. The ability to walk around without assistance.

AMBULATORY WITH ASSISTANCE. The ability to walk around with the aid of a cane, crutch, brace, wheelchair, or walker.

AUDIOLOGIST. A specialist with a graduate degree who is certified by the Ameican Speech-Language-Hearing Association. This specialist can identify and evaluate hearing problems and recommend and provide therapy to rehabilitate or enhance a person's hearing. The audiologist also specializes in determining when hearing aids are needed and will fit one for a patient.

BOWEL AND BLADDER TRAINING. A program to retrain a patient in bowel and bladder functions to minimize or eliminate incontinence.

BLOOD PRESSURE. The measure of the force exerted on blood vessel walls as blood is pumped from the heart.

CATHETER. A tube passed through the urethra into the bladder to drain urine.

CHORE SERVICES. Shopping, marketing, transportation, heavy cleaning and similar services available alone or in combination with homemaker-home health aide service. Costs for these services are usually *not* reimbursed by Medicare. Some agencies provide chore services only, without home health care or nursing supervision.

CHUKS. The trade-name for an absorbent pad which is soft on one side, waterproof on the other, and disposable. Used under incontinent persons or for draining areas of the body.

CONTINENT. The ability to control the passage of feces and urine.

DECUBITUS CARE. The care of a bedsore. Treatment includes medication and dressings; a nurse can instruct the patient on proper bed positioning to prevent further irritation.

DECUBITUS ULCER. (Commonly referred to as a bedsore). A sore or ulcer caused by lack of blood circulating to some area of the body. This condition usually results from sitting or lying too long in one position.

GRAB BARS. Railings placed on walls to steady oneself as a safety measure.

HOMEMAKER-HOME HEALTH AIDE SERVICES. Personal assistance and homemaking services provided in the home to sick or disabled persons who cannot perform basic tasks for themselves. Services provided include shopping, meal preparation, light housekeeping, assistance with personal care, administering oral medications under supervision, and reporting patient progress to the home health nurse.

PULSE. A measure of the rate and force of blood as it is pumped by the heart, which indicates the number of heart beats per minute.

REGISTERED NURSE (RN). A person who has successfully completed a minimum of two years of nursing education at an accredited school of nursing. Nurses must be licensed by the state in which they work. (Some graduate nurses can practice in certain states for a short time prior to passing a licensing exam.)

RESPIRATION. The act or process of breathing.

RESTRAINT. A protective device used to prevent a patient from falling out of a bed or chair (i.e., a belt around the waist or a jacket with straps which tie to a wheelchair.)

SELF-CARE. Bathing, dressing, toileting, and feeding oneself.

SHEEPSKIN. Used under or over a bed-sheet for softness and comfort; a soft natural or synthetic skin used to protect bony areas of the body.

SPEECH-LANGUAGE PATHOLOGIST. A person who has a graduate degree and is certified by the American Speech-Language-Hearing Association. The speech-language pathologist can assess the patient's problem, design a treatment program, and provide therapy to help the patient regain or maintain speech or language skills.

SOCIAL WORKER. Usually an employee of a home health agency or a social service department who is available to help a person adjust to confinement at home. The social worker also counsels family members in caring for the patient. If community services or financial assistance are needed, the social worker can recommend sources of help.

VITAL SIGNS. Pulse, temperature and respiration.

WALKER. A lightweight frame held in front of a person to provide stability in walking. A walker is more stable than a cane.

CHECKLIST FOR SELECTING A HOME HEALTH AGENCY (A)

SERVICES:	Name of Agency / Address / Phone # — Yes	No	Cost Per Visit	Reimbursement (Type & Rate)	Name of Agency / Address / Phone # — Yes	No	Cost Per Visit	Reimbursement (Type & Rate)
Nursing								
Physical Therapy								
Speech Therapy								
Occupational Therapy								
Homemaker & Personal Care								
Social Work								
Nutrition Therapy								
Dental Care								
Medical Supplies & Equipment								
SERVICE AVAILABILITY:								
Hours/day								
Days/week								
STAFFING (specify #):								
Supervisors								
RNs								
LPNs								
Homemaker-Home Health Aides:								
• Hours of initial training								
• Required hours of continual in-service education								
STAFF SUPERVISOR:								
—Assumes responsibility for care given								
—Qualifications								
—Visits Patients								
—Frequency of Staff Contact								
—Available in Emergency								
—Provides instruction to Homemaker-Home Health Aides								
MISCELLANEOUS:								
Current Operating License								
Frequency of Physician Consultation								
Waiting Period for Service								
Translators (Specify Language)								
Geographic Areas Served								
Certification by Medicare and/or Medicaid								
Written personnel policies, basic benefits and wage scale for each position								

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	Name of Agency Address Phone #				Name of Agency Address Phone #			
MISCELLANEOUS: (continued)	**Yes**	**No**	**Cost Per Visit**	**Reimbursement (Type & Rate)**	**Yes**	**No**	**Cost Per Visit**	**Reimbursement (Type & Rate)**
Public list of Board of Directors or Community Advisory Committee								
Annual report of operations available								
Written statement of who is eligible for service and under what conditions								

CHECKLIST FOR EVALUATING HOME HEALTH AGENCY SERVICE (B)

	Name of Agency Address Phone #		Name of Agency Address Phone #	
PHYSICIAN SUPERVISION:	**Yes**	**No**	**Yes**	**No**
Patient Can Call				
Physician Visits Patient				
Staff Consultation Weekly or Bi-Weekly				
STAFF SUPERVISION:				
Patient Can Call				
Supervisor Visits Patient				
Staff Consultation Weekly				
PATIENT/FAMILY SATISFACTION: (to be completed after service begins)				
Comfortable with staff				
Informed of Care Plan and Progress				
Observable Response to Treatment				
Questions/Concerns Answered				
Services Expected are Received				
Scheduled Visits Kept				
Needed Services Added				
Unneeded Services Terminated				
Periodic Reassessment of Care Plan				

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RESOURCES

PUBLICATIONS

Irwin, Theadore. **Home Health Care: When a Patient Leaves the Hospital.** New York: Public Affairs Pamphlet, 1978. (Available from Public Affairs Pamphlets, 381 Park Avenue South, New York 10016. Public Affairs Pamphlet #560. $1.00 each)

Nourse, Alan E., M.D. **A Guide to Home Health Care.** Kalamazoo, MI: Upjohn Health Care Services, 1980. (Available from Upjohn Health Care Services, 2605 East Kilgore, Kalamazoo, Michigan 49002)

Trocchio, Julie. **Home Care for the Elderly.** Florence, KY: Van Nostrand Reinhold Publishing Company, 1981. ($11.95)

National Home Care Associations

American Hospital Association
Division of Ambulatory and Home Care Services
840 N. Lake Shore Drive
Chicago, IL 60611
(312) 280-6000

Council of Community Health Services
National League of Nursing
10 Columbus Circle
New York, NY 10019
(212) 582-1022

Home Health Services and Staffing Association
2101 L Street, N.W.
Washington, DC 20037
(202) 775-4707

National Association of Home Care
205 C Street, N.E.
Washington, DC 20002
(202) 547-7424

National Homecaring Council
67 Irving Place
New York, NY 10003
(212) 674-4990

Caring for Your Aging Loved Ones: A three agency community service

by

David Turner, M.Ed.
Salt Lake County Aging Services
and
Alberta W. Blue, A.C.S.W.
Salt Lake County Mental Health

Since 1982, three agencies have cooperatively sponsored an education program for caretakers of aging persons. This program is an excellent example of interagency cooperation that must take place before effective nonduplicative services can be offered. The paper describes the coordination of efforts, success, problems encountered and solutions found for recruitment of participants.

Caring For Your Aging Loved Ones is not merely a community education series. For those of us who have worked with it, it has been an exploration of the dynamics in caretaking families, a lesson in how to market a class, and an exercise in development and format. The scope of this paper will range from a discussion of the issues as we see them, to a caveat about some of our marketing mistakes as well as our successes. Finally, we will describe how we designed the series, and suggest some possible resources for planners.

Caring for aging loved ones in large numbers is a responsibility that no society has ever faced . Since World War I, life expectancy and social changes have created a new group of dependent persons. The most rapidly growing age group in the United States is now the group over 85. Typically these persons are likely to be frail, poor and female.

Part of our society's folklore says that families were composed of three generations living in the same household. Actually, two generations have always been the norm. At the beginning of the century few people lived long enough to need any care. As the over 85 population increases, other trends are toward smaller families and working women. Hence, we see fewer available caretakers.

An even more destructive myth implies that the frail old are neglected by their families. The Commission on Elderly People Living Alone describes this population as 50 percent over 75 years old, 78 percent female and 45 percent in poor health. The majority of those who appear "abandoned" are childless or have children living in other cities.

The people who traditionally have been assigned a caretaking role are specific women in the family. A single, unmarried daughter was often "expected" to sacrifice herself for any frail parents. It is no wonder that middle aged married or unmarried women have been called the "caught" generation. (Newgarten and Hagestad, 1976:47) They are caught between their parents and their children as well as their careers and personal lives.

The conflict of roles for caretakers can cause enormous dissonance. It is quite possible for people in their middle years to simultaneously be parent, child, spouse, student, employee, grandparent and caregiver. Success in any role can lead to problems or failures in another. Self-imposed and/or socially imposed expectations are often unrealistic for anyone saddled with that many roles.

Not only do some caretakers take on more challenge than they can handle, but the whole family undergoes enormous stress in the crises of added caregiving. Relationships in a family are established early and change comes very gradually. When one member becomes frail a change of role may be forced on all the family members. Conflicts surface when expectations are unclear. Siblings begin to pass judgement on each other. Past conflicts and resentments surface. Spouses are required to learn new skills and children feel resentful because of perceived neglect. Families often do not understand the many changes that are happening. Expectations for behavior and support may not be realistic.

Many of us who work with older persons and their families recognize the difficulties inherent in the caretaking role. The

literature is full of research describing the problems. A major difficulty for community agencies is reaching caretaking families in the first place. Available help is of little value to those who are ignorant of it. It is not uncommon for families to avoid seeking help from a community mental health agency. Area agencies on aging have contact with a portion of the elderly population, yet their ability to communicate with adult children is very limited. Many a well meaning agency has offered a caretaker education series to the community, only to have no one show up.

Since 1982 three agencies serving the metropolitan area of Salt Lake have cooperatively sponsored a community education program for families of frail elderly. The program is designed to provide families with general information about age-related issues and needs as well as an introduction to the many community services which can assist families in their care-giving activities. Some of the series have been much better attended than others. It is clear to us that successful classes have resulted from successful marketing efforts. It is simply not good enough to offer a class and then automatically expect people to come. Certain marketing tools worked and others did not.

Unsuccessful advertising included a listing in the YWCA catalogue of classes. Those who need the experience most do not read class announcements. This may be true because the stress of care-giving leads to guilt when looking for an outside release. Also, it may be that the ability of the YWCA to distribute the catalogue is limited to Y members or previous enrollees. Posters

placed in senior centers and even in public places were not very helpful either. Posters compete with far too many other distractions.

Press releases usually result in small newspaper announcements that go unnoticed. Even an extensive article is not very useful if the publication has a limited readership. For example, some periodicals are read by older persons or by women in the work place (see appendix 1). In both cases, the message about an upcoming seminar series fails to reach its target audience. We found that potential participants did not read these publications.

In general, dependence upon a host agency such as the YWCA or a library to recruit participants results in small or nonexistent groups. The question, then, is what works?

First, it is important to emphasize the need for a program called Caring for Aging Loved Ones. The potential audience is there, because having a dependent elderly family member is becoming a normative experience. There is little good data about the numbers of people who are caring for their parents or other older persons. This is due largely to a lack of research. However, for every person living in a longterm care facility, there are two equally frail people who are cared for by their families. (Comptroller General of the United States, 1977a) Our informed experience with families indicates that our problem is not lack of people who need help, but the difficulty of getting the word out by a productive method.

We have been able to place major feature articles with photos in the local daily newspaper (see appendix). This is almost a

guarantee that a class will fill up. The problem is in attempting to repeat the article six months or even a year later. Large newspapers are reluctant to repeat themselves. The big article only works the first time.

A second source of enrollees is former class participants. We found that by sending an announcement to former participants, we had repeaters as well as an informed communication source to friends. Word of mouth, as any advertiser will verify, is still the most effective communicator. Maintaining and adding to a mailing list is vital; using it is essential.

A third idea that worked to some degree was a letter sent to ministers of the local churches and directors of local home health agencies. Church officials were more receptive if we had a specific name on the envelope. Otherwise, letters were lost in the plethora of junk mail.

By far the most successful single technique we have found for reaching potential class participants is radio. In thinking why this is so effective, it is important to focus again on the stress experience of the caretaker. Many of them have expressed to us the guilt they feel about "stealing" time for themselves. Reading, television and community education are activities that require one to engage one's time selfishly. Hence, people are reluctant to answer their own basic self replenishment needs.

On the other hand, it is possible to listen to the radio while tending to some other duty; parenthetically, it may not be acceptable to go to a movie or play tennis, yet it is okay to attend a class on how to be a better caregiver.

An interesting example of the influence of radio comes from one of our participants. She came to a crisis in the care of her father. Out of frustration to relieve her stress, she was driving up and down the highway when she heard one of the group leaders on the radio..Hearing this announcement prompted her to find out about the class and attend.

Radio has several different formats that serve our purpose. The first is the talk show. These programs vary from 30 minutes to an hour, often with several guests who discuss a single topic. A variation of the talk show is one that allows listeners to call in with questions and comments. An advantage of a talk show is that it allows discussion in some depth. It is a method of educating the public about needs and resources. The objective of the radio station may be a lively and controversial discussion. Sometimes this can be a drawback. A radio personality may attempt to harass a guest in order to keep the show exciting. A further problem is that a talk show can be a lot of work for one exposure.

A second format is a public service announcement. All stations are required to do PSA's and willingly read copy that is well written to fit into 60, 30, and 20 and 10 second slots. Broadcasting the PSA just prior to the beginning of the interview is beneficial. A personal contact with the station program director is very helpful (see appendix ___) to insure airtime at a reasonable time of the day.

A third format is radio promotions. These promotions have the potential to increase awareness of an event. The major problem with promotions is that they must be paid for. We have not had a budget

for such campaigns. Conceivably other commercial advertisers may be willing to attach tags about educational events in order to increase visibility and good will. Radio promotions can serve to help coordinate advertisers and community groups.

New programming is a fourth possibility. We have found that in a large radio market a community class is not considered news. That may not be true in small rural markets. News directors need to be convinced that the issue of caring for one's elderly is a newsworthy item. Back up material and local data may prove the point.

Of all the formats offered by radio, the most effective for us was the regularly repeated public service announcement. These announcements were not difficult to prepare, stations were usually very willing to run them and they were free.

Once a group has been gathered, the structure of the class can be decided. We have learned that it is not wise for group leaders to decide in advance what subjects must be covered or fix on a concrete schedule of speakers. Each group is different. Time to process, ventilate and express needs was often valuable for group leaders to find appropriate topics for each session. Our program is structured as six to eight weekly sessions. At least two sessions are best used for processing tasks. The time constraints and the diversity of participants are both factors that constantly challenge and limit group leaders. Much depth and detail must be skimmed or ignored in this type of program. Our intent in providing information is to help families with a "beginning roadmap" that can point to some to alternatives that they can later explore as appropriate to their particular situations.

The two group leaders are community-based gerontologists who have extensive experience in both educational and clinical models of group work. Both are actively involved with both formal and informal service providers throughout the area, which has enabled them to obtain the time of "guest experts" as well as extensive printed literature for distribution.

We have found that most agencies welcome an opportunity to provide public education. A single caveat may be to avoid personalities who are intent on selling a particular product or service. The topics we generally include are normal aging vs. illness, medications, emotional needs of both the elderly and family, legal and financial considerations, and the continuum of care services such as adult day care, Meals on Wheels, home health care and nursing homes. Throughout the series there are three themes we try to communicate:

1. "You are not alone." Others have and are experiencing many of the same situations, and have found healthy ways to cope.

2. "There is help out there." Often families do not learn of available supports until months or years after they could first be used.

3. "There is no one right way to care." We try to encourage all group participants to begin to examine and discuss options within the reality of their own family situations.

Caring for your aging loved ones has proven to be an effective means of reaching and supporting some of the many families in our community who serve as primary caregivers for their elders. The job of recruitment is just as important as the quality of the classes.

It is both feasible and cost effective for our agencies to offer Caring for Your Aging Loved Ones to the community. Our participants tell us that we are reaching those who most need this information and support.

The classes give them the tools they need to take more control of their lives and more effectively meet the needs of the whole family.

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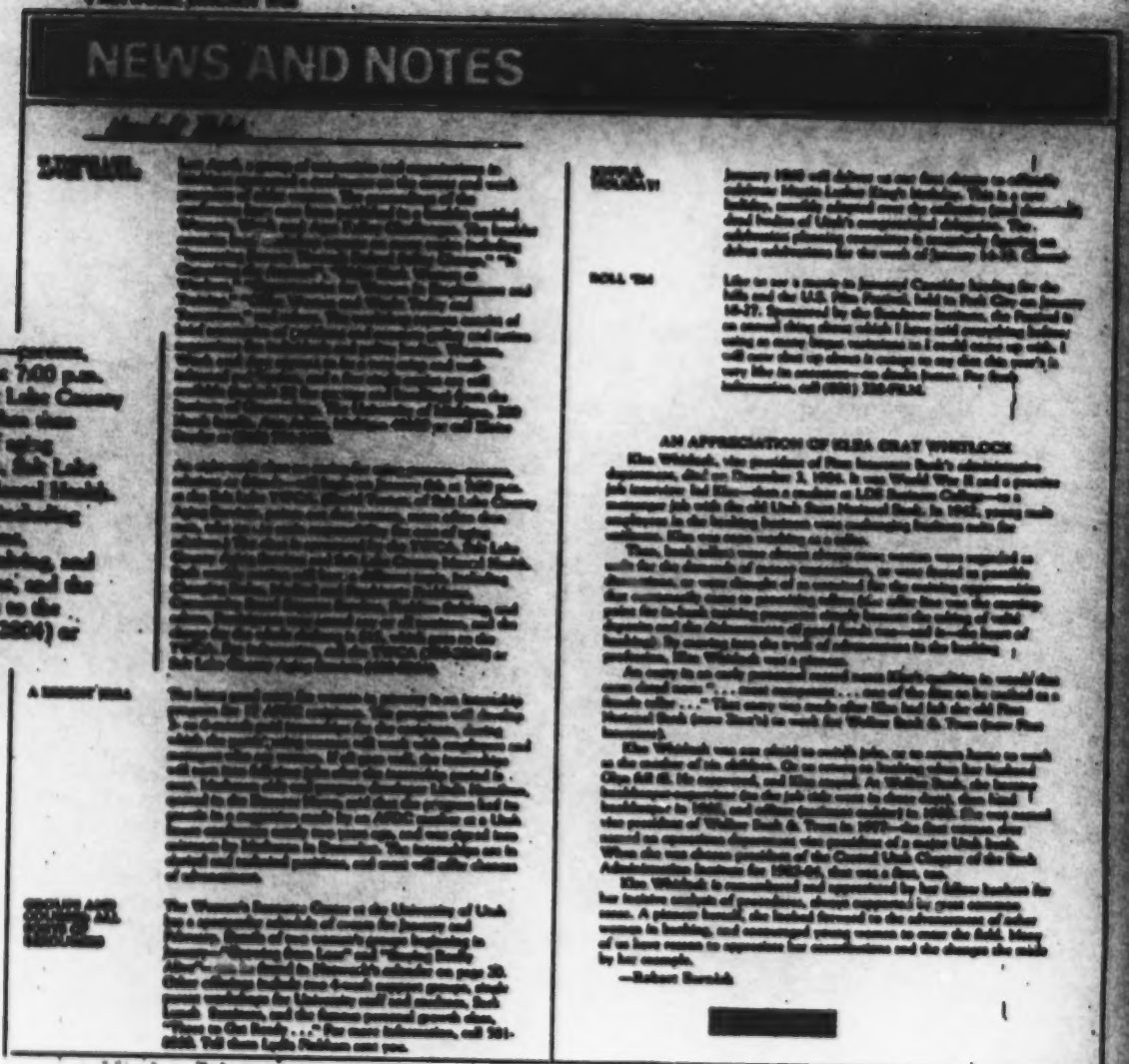

NEWS AND NOTES

STICKING TOGETHER

An eight-week class on caring for aging persons—parents, relatives or friends—will begin on January 8th at 7:00 p.m. at the Salt Lake YWCA. (David Turner, of Salt Lake County Aging Services, points out that women, more often than men, take on the main responsibility for care of aging relatives.) The class is sponsored by the YWCA, Salt Lake County Aging Services and Salt Lake County Mental Health. Each weekly session will have a different topic, including Changing Roles, Medical and Psychiatric Problems, Community Based Support Services, Problem Solving, and others. Participants may attend any or all sessions, and the charge for the whole shebang is $15, which goes to the YWCA. For information, call the YWCA (355-3904) or Salt Lake County Aging Services (488-5764).

AN APPRECIATION OF ELSIA GRAY WHITLOCK

Elsa Whitlock, vice president of First Interstate Bank's administrative department, died on December 3, 1990. It was World War II and a popular job interview led Elsa—then a student at LDS Business College—to a summer job with the old Utah State National Bank. In 1942, young male employees in the banking business were undergoing hardware tests for enlistees. Elsa was soon working as a teller.

Then, bank tellers were almost always men; women were regarded as unfit for the demands of money transactions, or were found to possess shortcomings, or were thought of as suspect for the exciting opportunities that occasionally came to promising tellers (for after Elsa was the country going for its bank-starving prospects simply because the ruling of valid deposits and the determination of good funds was—and is—the heart of banking). By moving into the world of advancement in the banking profession, Elsa Whitlock was a pioneer.

As many as are only personal record were Elsa's qualities to record that were dated were "... most competent ... one of the first on by method as a female teller ..." That story was made after Elsa had left the old First National Bank (now Bank's) to work for Walker Bank & Trust (now First Interstate).

Elsa Whitlock was one ahead to switch jobs, or to return home to work as the mother of six children. Or as many as banking when her husband Glen fell ill, he recovered, and Elsa stayed. At Walker Bank, she became housing-supervisor for the job title went to three deans, then head bookkeeper in 1955, and other positions ended in 1980. She was named the president of Walker Bank & Trust in 1977—the first woman ever named an operations department vice president of a major Utah bank. When she was chosen president of the Central Utah Chapter of the Bank Administration Institute for 1982-83, that was a first, too.

Elsa Whitlock is remembered and appreciated by her fellow bankers for her business methods of procedures, always supported by great common sense. A pioneer herself, she looked forward to the advancement of other women in banking, and encouraged young women to enter the field. Many of us have reason to appreciate her encouragement and the changes she made by her example.

—Robert Burdick

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APPENDIX 2

Survival Strategies for Divorced Women L 434

Offered through the YWCA Howard Parmen Service

This informative group will provide a comfortable and supportive environment where divorced and separated women can discuss their individual problems and concerns. Selected topics of discussion will help participants determine their needs, learn coping strategies, and become aware of community resources available to them. Topics discussed will include:

- overview of problems facing divorced women
- emotional reactions—dealing with guilt, depression, rejection, anger
- building confidence and self-esteem
- stress management
- single parenting
- information on employment opportunities and job training programs

Child care will be provided in the play center for pre-school children. There is a fee for child care, however, that will be waived or reduced depending on financial situation.

All participants should pre-register.

Time and Days: Wednesday afternoons beginning Jan. 25th 1:00-3:30 p.m.

Fee: No fee —6 sessions

Financial arrangements will be made if necessary.

Personal Financial Planning L 436

Do you often wonder why you have no money and "nothing to show for it?" Knowing expenditure of needed money now, or knowing should develop a personal financial plan. This program will help you determine what you can afford, how to use your money to your best advantage, how to prepare for [illegible], and methods of controlling your finances. Topics of discussion will include: checking, credit, budgeting tips, and methods of establishing financial programs such as savings accounts, money market funds, and investments. Individual problems will be discussed during a consultation period with Eathryn Pelton, and a variety of financial [illegible] and a will workbook.

Instructor: Eathryn Pelton, is a graduate of the University of Utah Law School and is an Assistant Executive with Thurston Stoffmont Securities.

Day and Time: Tuesday, 6:30-8:30 beginning January 17th

Fees: $20.00 Single—4 sessions
$30.00 Couples

Music Related Activities for Children H 433

0-3 Years of Age

This workshop is for parents who would like to learn music related activities to share with their children at home. Topics discussed will include:

- vocal perception
- rhythm activities
- large and small muscle development
- physical games and listening activities
- how music helps develop pre-reading and pre-math skills

Designed for parents of children 0-3 years of age with additional information for those available.

Instructor: Barbara [illegible] is a certified elementary teacher with an early childhood endorsement. She is presently working on a licensed day care provider.

Day and Time: Tuesday 9:30-11:30 January 23rd and 30th

Fee: $10.00—2 sessions

Survival for Pre-School Parents L 412

A recreational workshop designed for parents of pre-school children to help children and parents survive. Practical discussion suggestions for [illegible] of parent-child relationships, [illegible] and self-esteem. Other topics discussed will include: [illegible] sibling rivalry, bedtimes, responsibilities, communications, and separation. Studies in [illegible] of pre-school children, helping parents/friends, and counseling to be a "good mother" will also be discussed.

Instructor: Judy Hedlund, M.A. Licensed Individual, Marriage & Family Therapist in private practice and mother of 2.

Required text for class: Your Child's Self-Esteem by Dorothy [illegible] Tennes purchase before class.

Playmates available.

Time: 9:30 to 11:30 a.m.

Fee: $25.00—7 sessions

Infant Stimulation H 102

Learn how to strengthen the parent/infant bond through baby massage, games, exercises, and fun. Topics discussed will include: nutrition, toys, and self-esteem.

Time: [illegible] beginning Jan. 19 1:00-2:00 p.m.

Fee: $12.00—4 sessions

Designed for infants from newborn through 10 months. Contact the YWCA for further information.
Individual financial arrangements will be made if necessary.

Caring for Your Aging Loved Ones L 411

This class will address the changing needs of the older person as well as the needs of the caregiver, and give suggestions and options for dealing with the physical and emotional conflicts that often occur in the changing relationships between parents and children. Topics to be discussed include:

- **—interpersonal relationships, dealing with the changing responsibilities, expectations, and conflicting views**
- **—legal and financial issues**
- **—existing institutional supports and community services**
- **—perspectives on aging, discussed by aging people**
- **—health and nutrition, with special emphasis on effects of drugs**

Besides being helpful to people working with their aging parents, it would also be beneficial to those involved with any aging loved one, such as a spouse, close friend, or other close relative. There will be experts in the different fields addressing the issues, and time allowed for discussions, and questions.

Facilitated by Alberta W. Blue A.C.S.W. of Salt Lake County Mental Health in cooperation with Salt Lake County Aging Service.

Time and Day: Tuesday evenings at 7:00 beginning Jan. 17th
Fee: $10.00—6 sessions.

Touch For Health I H 400

Instructor: Shelyn J. Turner

A new approach to restore our natural energies. Learn to use natural methods, including compressure and massage to improve postural balance and to relieve physical and mental pain and tension.

Time: 1:00 to 3:00 p.m.
Time: 7:00 to 9:00 p.m.

Fee: $20.00 plus $12.00 for textbook.
6 sessions.

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YWCA offers variety of programs

By Sue Thurmon
Deseret News special writer

After 70 years of unselfish giving the YWCA is firmly rooted in city soil. But even though the organization has been responsive in meeting community needs, some residents are unaware of the variety of programs the Y has to offer.

An open house to acquaint residents with the Y (and each other) is planned for Thursday, Sept. 13 from 9 a.m. to 2:30 p.m. at the facility, 322 E. 300 South. Workshops are free, and anyone interested may sign up before hand at the Y office, or the morning of the open house. Child care will be available.

Workshops include:

Fitness and Aerobics, 9:30-10:30 a.m., and noon to 1 p.m. There will be discussion and activity, and those attending may participate or simply observe.

Aquacise, 10:30-11:25 a.m., and noon to 12:05 p.m. Participants should bring a suit, cap and towel.

Diaper Gym-Swim is for parents and children aged 6 months to three years. Gym is from 10:45 to 11:15 a.m., and swim from 11:30-noon.

Home Activities for Parent and Child, 9:30-10:15 a.m. Crafts for those long afternoons at home will be taught, and parents also will be introduced to the many activities the Y has to offer preschoolers.

Women on Target, noon-12:45 p.m. This is a self-motivating health promotion program for women taught by Sherrie Street.

Women in Jeopardy, 10:30-11 a.m., and 12:30-1 p.m. This Y program serves battered women and their children by providing a safe residence and counseling.

ILLUSTRATION/CHRISTIE JACKSON

Throughout the day tours of YWCA facility and explanations of various programs will be offered. For further information or sign-up call 355-2004.

In the beginning the Y was established as a safe residence hall for women seeking employment in the city. A summer camp in Emigration Canyon was established shortly thereafter as an inexpensive way to spend summer vacations.

By 1917 a YWCA secretary was meeting incoming trains, offering women and children a safe place to stay until permanent quarters could be found.

During the wars the Y held open house for soldiers and provided recreation facilities for the servicemen. After the war, the Y offered classes in English and programs of fellowship to refugees and Japanese relocatees.

Throughout the years the Y has provided strong support for social issues, such as women's suffrage, child labor laws, and improved wages for women employed in industry and at less than worthy jobs. In 1918 a contract was negotiated with the Division of Child Welfare to use the third floor of the YWCA residence as a halfway house for women prisoners.

In 1937 the Women in Industry division was established and one of the early work programs in the city. That same year the Y began Colored Women's Division and in 1941 a program for girls of Japanese ancestry was established. Other changes in the years that followed as organized youth groups with special services started for the underprivileged, physically handicapped and children of low-income families. Many programs focused on race relations.

A Y Teen Board, for pregnant teenage girls, who have nowhere else to go, also was founded. The Y continues to provide support services for displaced persons, Alzheimer, retired individuals, women from other countries living in S.L., and students.

In addition to these social programs the Y still offers swimming, fitness and gym classes, as well as life enhancement courses, such as stress reduction and meditation, cooking for one, personal banking, preserving and managing money.

The Y's responsiveness to changing community needs is a result of a diverse group of volunteers, who reflect the organization's imagination to eliminate racism where it exists and by whatever means necessary. Rooted in the Christian faith, the Y desires to draw together women and girls of diverse experiences and religions that their lives may be open to new understanding and deeper relationships.

Workshop planned on aging issues

SL Tribune Sept 17, 1982

A special seminar, "Caring for Your Aging Loved Ones," sponsored by the Young Women's Christian Association, Salt Lake City, to address the changing needs of the older person as well as needs of the caregiver, is being scheduled for six weeks, beginning Tuesday at the YWCA Activities Building.

Suggestions and options for dealing with the physical and emotional conflicts which often occur in the changing relationships between parents and children will be a focus.

Topics to be discussed each Tuesday include "Interpersonal Relationships. Dealing With the Changing Responsibilities, Expectations and Conflicting Views," by Elaine Bennett, MSW; "Legal and Financial Issues," by Justin Stewart, attorney, chairman, Committee for Legal Protection of the Elderly; and Afton Peregrun, field representative for the Social Security Administration; and "Health and Nutrition," Radell Ashley, Utah State Department of Health, and Dottie Williams, consultant for the elderly, with Jog Jass.

Shauna O'Neil, director of Salt Lake County Aging Services and Helen Kuhn, Community Nursing Services, will discuss, "Existing Services"; "Dealing With the Feelings," focusing on developing a better understanding of the psychological, emotional and spiritual dynamics of aging family members, will be discussed by Alberta W. Rhe, gerontologist and clinical social worker for the Salt Lake County Division of Mental Health.

Mrs. Bennett will further develop the topic at the concluding Oct. 30 session.

Registration is being taken at the YWCA.

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Destroying the myths about aging

By Sue Thurman

Aging is inevitable, but the inevitable needn't be devastating. As a larger portion of the population lives longer research is currently underway to determine what is "normal" aging, and what can the aged as well as their caretakers expect.

In an attempt to provide information, destroy myths, and put caretakers in touch with community resources, three agencies have joined to provide a six-week class — "Caring For Your Aging Loved Ones."

Co-sponsors are the YWCA, Salt Lake County Mental Health and S.L. County Aging Services. The sessions will be held Tuesdays, 7 p.m. (beginning Jan. 17) at the Y, 322 E. 300 South. There is a $10 fee for the class. Anyone interested may contact the Y, 355-2895.

Coordinators of the course are David Turner, M.Ed./gerontologist, who is substance abuse education coordinator for S.L. County Aging Services; and Alberta W. Blue, ACSW, clinical social worker/gerontologist, who is coordinator of continuing care for the Southeast Outpatient Unit, S.L. County Mental Health.

These professionals will identify the normal aging process and common family patterns of coping. They also will help class members develop action plans for the future.

Other experts in the field of aging will discuss common medical and psychiatric illnesses, financial and legal issues, health screening and medications, and community services and alternatives.

The class is targeted for caretakers since primary care of the aged falls to the family, generally to a woman. Many middle-aged caretakers find themselves caught between caring for their aging parents and their own teenage children. And although only one person is aged, aging seems to affect the entire family.

Several misconceptions surround the aging process, since not much was known about it until recently. Common myths include belief that everyone will get senile, that everyone will eventually need a nursing home, that families don't care so they dump their elderly, that everyone will experience similar physical factors such as going deaf and blind, and developing osteosclerosis.

"These thoughts are simply not true," states Blue. "Aging is not a disease. We collect our own physical disfunctions as a result of genetic make-up and lifestyle, but not as a matter of aging."

The primary mental illness of the aged is not senility, but depression. This can be cured, but often goes undiagnosed and thus untreated. Alcoholism, too, is treatable if it's something that just started as the person grew older.

Recently researchers have discovered that the interaction of drugs accounts for a lot of the aged's problems.

According to Turner, 80 percent of persons over 65 have three or more chronic illnesses. If they are taking medications for these illnesses the drugs are all interacting in the body.

"Our bodies don't absorb medications the same way they did when we were younger," he states. "The interaction of medications can sometimes account for the elderly acting 'funny.' Caretakers should always question doctors to ask if medication changes are appropriate for the aged person. Unfortunately, most drug testing is done with 18-year-olds, whose bodies respond differently."

David W. Turner

Alberta W. Blue

In S.L. County 12 percent of the population is over the age of 65 (which coincides with national statistics). About 3 percent of the people seen in mental health centers are aged, and 30 percent of the money spent on medications and over-the-counter drugs is spent by the elderly.

The gerontologists say the elderly can anticipate changes, but these changes are not necessarily positive or negative. For instance, there is a slowing down of muscle reaction and neuro-transmission. Short-term memory may not be as sharp, but long-term memory remains the same.

In addition, there are social changes and role shifts as spouses retire or become widowed, etc. Researchers are just beginning to define these natural aging factors.

"Families are interdependent," states Blue. "They need to and should rely on each other, but in a functional, supportive way. Families need to recognize the strengths and needs of each person. A caretaker shouldn't give up her social and physical needs to meet the needs of her aging parents. If this is allowed to happen, several become victims of one person's situation."

In order for healthy coping to take place the instructors offer several suggestions. They encourage caregivers to support appropriate independence and self-management. It may be easier to do things for the aged. Time to help them figure out new ways of coping, but the message is totally different.

For instance, it may be expedient to show up with a casserole each night for the aged widower, but the message he receives is "I can't handle things on my own."

"Decisions often move too quickly in families," identifies Blue. "Well then we move mother in with the family. That is not necessarily so. Mom needs time to grieve and figure out her day-to-day living, and families need time to talk about decisions and their ramifications. Decisions are always complex, affecting a lot of people."

Turner says, "Even if the adult is frail, the relationship between the elderly and his family will be better if he is allowed to make decisions and care for himself. When decisions are made, the door should always be left open for re-evaluation.

"Family meetings should be held in a neutral place with an agenda and ground rules," continued the gerontologist. Members should feel free to express what they can and can't do."

The instructors of the class encourage caregivers to build their knowledge and awareness of the aging process, to be assertive when seeking help, to question diagnoses and to be realistic when responding to the needs of the elderly. (The elderly can be very manipulative). They also suggest caretakers check around if they don't feel comfortable with the information they've been given.

"The problem is not the old person," states Blue. "Often the problems is not knowing what to do."

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COUNCIL FOR THE AGING

SHAUNA O'NEIL
DIRECTOR

FAMILIES AND AGING

Resources for Families

ACTION WITH THE ELDERLY: A HANDBOOK FOR RELATIVES AND FRIENDS by Kenneth Keddie, a Scottish author. Although discussion of programs is not applicable to the United States, families should find most of the information helpful. Offers suggestions to help the older person to be independent and to ease the work of the caregiver. (Pergamon Press Maxwell House, Fairview Park, Elmsford, New York, 10523, 1978; $23.00, Paperbound $9.75.)

AGING IS A FAMILY AFFAIR by Victoria Bumagin and Kathryn F. Hirn. Excellent handbook for both the middle-age and older generations. Covers all aspects of aging and intergeneration communication. (Thomas Y. Crowell, 666 Fifth Avenue, New York, 10019; 1979; $11.40.)

AGING PARENTS AND DILEMMAS OF THEIR CHILDREN by Bert Kruger Smith, Jacqueline LeLong, and Bettina Adelberg. A 26-page bulletin presenting general information about family adjustments in later life, nursing home placement of an elder, and the design and content of a discussion series for families. (Hogg Foundation for Mental Health, University of Texas, Austin, Texas 78712; 1981; Single copies available free.)

CARING FOR YOUR AGED PARENTS by Earl and Sharon Grollman. Using a prose format, provides concise information and insights on aging related problems faced by families. Does not provide in-depth information. Offers few solutions to problems. (Beacon Press, Harper and Row, Keystone Industrial Park, Scranton, PA 18512; 1978; Paperback $4.95.)

CUTTING LOOSE by Howard M. Halpern. A guide for adults of all ages who experience difficulty in their interactions with parents. Provides understanding and suggestions for dealing with parents who give double messages; play a "martyr" role; rule through fear and belittlement; are unloving; criticize continuously; are seductive; or sow conflict in relationships. Emphasizes the importance of distinguishing old "song and dance" from the realistic need of aging parents to be dependent on adult sons and daughters. (Bantam Books, New York, 1981; $2.75.)

FOR GRANDPARENTS: WONDERS AND WORRIES by Myron and Mary Maddon. Discusses the grandparent/grandchild relationship, how grandparents can support their children in the parenting role, and intergenerational living. Has a religious orientation. (The Westminister Press, 925 Chestnut St., Philadelphia, PA 19107; 1980; $5.95.)

HELP FOR FAMILIES OF THE AGING by Carl [illegible] and Jane Heald. Includes a workbook (eleven structured lessons) and three forty-minute cassette tapes. Designed for independent use by small groups of family caregivers to help them deal with emotional responses to changes in relationships with aging relatives; identify solvable problems; generate alternatives and determine which action is most appropriate for their situation. [illegible] Center for Families of the Aging. P.O. Box 245, Swathmore, PA 19081; 1982; $18.95.)

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HOME CARE OF THE ELDERLY by Julie Trocchio. Gives basics of home nursing care, guidelines for deciding whether or not to provide home care, and methods for managing health conditions of older adults. (CBI Publishing Company, 51 Sleeper Street, Boston, MA 02210; 1981; $8.95.)

I LOVE YOU BUT YOU DRIVE ME CRAZY: A GUIDE FOR CARING RELATIVES by Ann Calder and Jill Watt. A basic manual for caregivers. Suggestions given for coping with problems, choosing doctors, involving others in caregiving, and selecting care facilities. Emphasizes the importance of caregivers meeting their own needs. Includes questionnaires and work sheets for self-evaluation and decision-making. (Fforbez Publications, 2133 Quebec St., Vancouver, Canada V57; 1981; $6.95.)

MANAGING THE PERSON WITH INTELLECTUAL LOSS AT HOME by Fletcher McDowell. A practical manual. Gives suggestions for managing people who have lost their intellectual abilities and techniques for resolving problems. (Burke Rehabilitation Institute, 785 Mamoroneck Avenue, White Plains, NY 10605; 1980; $3.00.)

TAKING CARE OF OLDER PEOPLE AT HOME by John Agate. A guide for caregivers. Discusses management of problems such as disability, communication, mental illness, incontinence, and death. (George Allen and Unwin, 198 Ash St., Reading, MA 01867; 1979; $13.50; Paperback $4.50.)

THE BEST FRIEND YOU'LL EVER HAVE by Bernard Sloan. The author shares his experience of his aged mother living with his family and explores generational problems. (Crown Publishers, 1 Park Avenue, New York, NY 10016; 1980; $9.95.)

THE OTHER GENERATION GAP: THE MIDDLE AGED AND THEIR AGING PROGRESS by Stephen Z. Cohen and Bruce Michael Gans. Discusses older parent/adult child relationships, age-related changes, ways adult children can effectively assist older parents, and issues of independence/dependence and institutionalization. (Follette Publishing Company, 1010 West Washington Blvd., Chicago, Illinois 60607; 1979; $11.40; Paperback $2.95.)

THE 36-HOUR DAY by Nancy Mace and Peter Rabins. A comprehensive guide for families caring for a person with Alzheimer's Disease or other dementing illness. Practical advice given for all aspects of home management and guidance given for choosing a long-term care facility. (Johns Hopkins University Press, 3400 N. Charles, Baltimore, Maryland 21218; 1982; $14.95; Paperback, $6.95.)

UNDERSTANDING AGING PARENTS by Andrew and Judith Lester. Examines the adult-child/aging parent relationship and offers practical advice for dealing with one's own feelings and those of one's parents. Primarily focuses on physical and mental changes, death, loss, and grief, and decisions about living arrangements in later life. Has a religious orientation. (The Westminister Press, 925 Chestnut Street, Philadelphia, PA 19107; 1980; $5.95.)

WHAT DO I DO? by Katherine L. West. A practical guide designed to help families understand the needs of nursing home residents. Suggestions given for caring for, comforting, and communicating with institutionalized, older family members. (Amata Graphics, P.O. Box 12313, Portland, OR 97212, 1981; $5.00.)

WHAT HAPPENED TO MY MOTHER? by Henry Edwards. A personal account of one family's experience in dealing with mental illness in their 62-year old wife and mother. (Harper and Row, 10 East 53rd Street, New York, NY 10022; 1981; $10.50.)

WHEN YOUR PARENTS GROW OLD by Jane Otten and Florence Shelley. Provides resources and information for coping with the problems of aging parents. Topics include finding help in the community, money matters, diseases of older people, behavior changes, and selecting a nursing home. (Funk and Wagnalls Company, c/o Harper and Row, 10 East 53rd Street., New York, NY 10022; 1976; Paperback $2.25.)

YOU AND YOUR AGING PARENT by Barbara Silverstone and Helen Hyman. One of the most complete books on the subject of helping the adult children faced with problems of aging parents. Provides detailed information about community and institutional sources of help. (Pantheon Books, Random House Publishers, 400 Hahn Road, Westminster, Maryland 21157; 1981; Paperback $8.95.)

Bumagin, Victoria E. and Kathryn P. Him. Aging is a Family Affair. N.Y.: Lippincott and Crowell Book, 1979.

Cicirelli, Victor G. Helping Elderly Parents: The Role of Adult Children. Boston: Auburn House Publishing Company, 1981.

Gilles, John. A Guide to Caring for and Coping with Aging Parents. Nashville, Tenn.: Thomas Nelson Publishers, 1981.

Goodman, Jane G. Aging Parents: Whose Responsibility? Family Service Association of America, 44 East 23rd Street, N.Y., N.Y., 1980.

Schwartz, Arthur N. Survival Handbook for Children of Aging Parents. Chicago, Follet, 1977.

Silverman, Alida G., Carl I. Brahce and Carol Zielinski. As Parents Grow Older. Child and Family Services of Michigan, 9880 East Grand River, P.O. Box 548, Brighton, Michigan, 48116, 1981.

Springer, Dianne and Timothy H. Brubaker. Family Caregivers and Dependent Elderly: Minimizing Stress and Maximizing Independence. Beverly Hills, CA.: Sage Publications, Inc., 1984.

White, Diana and Margaret Neal. A Guidebook for the Family and Friends of Older Adults. Portland, Oregon: Institute on Aging, Portland State University, 1981.

NEWSLETTERS AND PAMPHLETS:

Cohen, Stephen Z. Bridging the Other Generation Gap. Philadelphia, PA., Colonial Penn Group, Inc., 19181, 1980.

Your Aging Relatives: How You and Your Family Can Help Them. Spring House, Pennsylvania, 19477, 1980.

Change. Newsletter of the National Support Center for Families of the Aging, P.O. Box 245, Swathmore, PA., 19081.

FEELINGS OF BURDEN AMONG ADULT CHILDREN CARING FOR AGED PARENTS: RESULTS OF A PILOT STUDY

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Abstract

Reported in this paper are the findings of a pilot study of 171 adult children who are currently providing support for aged parents. Key variables measured in the study included perceptions of burden (using the Caregiver Burden Scale) and family coping strategies (using the Family Crisis Oriented Personal Evaluation Scales - F-COPES). Caregiver characteristics and coping strategies were examined in terms of their relation to burden scores. Correlated with burden scores were the following variables: Sex of caregiver, number of dependent children in caregiver's home, perceived impact of caregiving on caregiver's health, and three out of eight coping strategies.

Introduction

Contrary to social myths that paint a portrait of family neglect of the elderly, research has repeatedly documented the fact that families, especially spouses and adult children, function as a primary source of care and support for aged members (Shanas, 1979a, 1979b; Shanas, 1980). However, accompanying these optimistic reports regarding the role of the family in caregiving are additional studies focusing on the experience of rendering support to eldery family members, almost all of which emphasize the stresses and burdens of care (Cantor, 1975, 1980; Montgomery, Gonyea & Hooyman, 1985; Pratt, Schmall, Wright & Cleland, 1985).

Caring for an aged parent, and particularly a parent beset by poor health, is extremely taxing. The caregiver (usually a daughter) often faces some degree of social isolation; lack of

time for self, family and friends; career interuptions; financial drain; and the unrelenting sense of responsibility for the well-being of the parent. These and other problems contribute to a subjective sense of burden experienced by many caregivers (Zarit, Reever & Bach-Peterson, 1980).

While previous studies of caregiving have documented a relationship between caring for an older parent and burden, only a few have focused on the specific correlates of burden (Montgomery, Gonyea & Hooyman, 1985; Zarit, Reever & Bach-Peterson, 1980). Specific resources, coping strategies, caregiver characteristics, and other factors that might mediate the sense of burden have not been fully explored. The purpose of this paper is to help clarify the relationship between feelings of subjective burden and (a) characteristics of the caregiver, and (b) caregivers' coping strategies.

Methods

Data Collection and Respondent Characteristics

The findings reported here are derived from data collected for a descriptive study in which questionnaires were mailed to 290 adult children providing some level of care and support for an aged parent. Names and addresses of potential respondents were identified primarily by asking students enrolled at Colorado State University if they knew of anyone currently providing care for an elderly parent. Additional names and addresses of caregivers were obtained from an adult day care program, the membership of several churches, and from the rosters of partici-

pants enrolled in workshops on issues related to personal aging and family care of the elderly.

Of the 180 questionnaires that were returned, 171 were deemed complete enough to be included in the present analysis. The demographic characteristics of the respondents included in this analysis are presented in Table 1.

Table 1.
Demographic Characteristics of Caregiver

Characteristic	n	%
Sex		
Male	50	29.2
Female	121	70.8
Marital Status		
Married (living with spouse)	149	87.1
Married (living apart from spouse)	3	1.8
Widowed	4	2.3
Divorced or legally separated	12	7.0
Never married	3	1.8
Employment Status		
Employed full-time	83	48.5
Employed part-time	31	18.1
Unemployed (but not retired)	6	3.5
Full-time homemaker	29	17.0
Retired	15	8.8
Other	6	3.5
No response	1	.6

Note: Age (median) = 51.58; Years of education (median) = 15.5

The mailed questionnaire solicited information on a number of variables, including characteristics of both the parent and the caregiver, the caregiving situation itself, the extent to

which the caregiver had planned for the time when care would be needed, the perceived impact of caregiving on the caregiver's marriage and family life, and the use of resources (including siblings and other family members) in the fulfillment of caregiving responsibilities. Of central importance to this analysis were sections that measured the caregiver's coping strategies and perceived sense of burden. Scales measuring these latter variables are described below.

Operationalization of coping strategies. Caregiver coping strategies were operationalized using the Family Crisis-Oriented Personal Evaluation Scales (F-COPES). F-COPES consists of 30 items that represent eight family or individual coping strategies in response to problems or difficulties (McCubbin, Larsen & Olson, 1981). F-COPES identifies the frequency (on a five-point scale: 1 = never; 5 = very often) that a respondent uses each of three internal and five external coping strategies. The three internal strategies are: reframing (the ability to redefine stressful experiences in a way that makes them more understandable and manageable), confidence in problem-solving, and passivity (avoidance responses to problems). The five external coping strategies focus on the degree to which families (or caregivers, in the current study) use different social support sources: Spiritual support, extended families, friends, neighbors, and community services. The F-COPES has a reported alpha reliability of .86 and test/retest reliability of .81 (Olson, McCubbin, Barnes, Larsen, Muxen & Wilson, 1983).

Operationalization of subjective burden. Caregivers' feelings of burden were measured using an adapted version of The Caregiver Burden Scale (Zarit, Gatz & Zarit, 1981). The Caregiver Burden Scale consists of 22 items on feelings about caregiving and has a reported alpha reliability coefficient of .79 (Zarit, 1982). Examples of items include: "Do you feel you feel uncertain about what to do about you relative?" "Do you feel your social life has suffered because you are caring for your relative?" "Do you feel you could be doing more for your relative?" and "Overall, how burdened do you feel in caring for your relative?" In the present study, both the instructions prefacing the scale as well as the scale items were re-worded so that term "relative" was replaced with "parent". Each item is rated on a 5-point scale, from zero (never) to four (nearly always). The caregiver burden score is the sum of all the responses across the 22 items, the range of which is from 0 to 88.

Findings

Caregiver Characteristics as Correlates of Burden

The mean caregiver burden score was 26.86 (SD = 14.14). There were no significant differences in burden scores by caregiver's age, income, education, marital status, sibling position ("only" child versus caregivers from multiple sibling families), the parent's place of residence (living in own home, with the caregiver, or in an institution), or caregiver's current self-rated health.

Caregiver characteristics that were related to feelings

of burden included caregiver's sex, number of dependent children and, curiously, caregiver's assessment of how caregiving had affected his/her health (in contrast to rating of current health status).

Caregiver's burden scores differed significantly according to sex of caregiver ($t = 2.74$, $df = 85$), with women indicating higher feelings of burden than men. The number of dependent children in the caregiver's home was also significantly related to burden scores ($r = -.15$), with those caregivers who still had dependent children at home feeling greater burden than those who either did not have children or who had already entered the "empty nest".

Several studies on caring for the elderly have indicated that caregiver's current health is an important correlate of feelings of burden (e.g. Pratt, et al., 1985). In the present analysis, caregiver's self-rating of current health status was not significantly correlated with subjective burden ($r = .13$). However, caregivers' response to the question, "If your health has declined since you started providing care and support to your parent, to what extent has caregiving affected this change?", was correlated was burden ($r = -.43$). Adult children indicating that caregiving had negatively affected their health had significantly higher burden scores than those reporting that their health had been affected (negatively) very little or not at all by the responsibilities of caregiving.

Of particular interest in this study was the relationship between coping strategies (measured by F-COPES) and burden. Consequently, zero-order correlations were computed between caregivers' scores on the eight coping strategies measured in F-COPES and subjective burden. These correlations are presented in Table 2. One internal strategy (confidence in solving problems) and two external strategies (support from neighbors and spiritual support) were found to be negatively correlated with burden.

Table 2.
Zero-Order Correlations of Subjective Burden with Internal or External Coping Strategies

Coping Strategy	r
Internal	
Confidence in problem solving	-.32**
Reframing	-.09
Passivity	.02
External	
Use of extended family	-.06
Use of friends	.005
Use of community resources	.02
Use of neighbors	-.15*
Use of spiritual supports	-.21**

* $p \leq .05$ ** $p \leq .01$

Since caregiver's sex was found to be significantly related to burden, the data on coping strategies were further analyzed for sex differnces, particularly to see if male versus female caregivers differed on those coping strategies that were most highly correlated with burden. Results of this analysis indicated while there were significant sex differences on several

coping strategies (use of extended family, friends and community resources), there were no sex differences on those coping strategies that had the highest correlation with burden.

Addressed, too, was the question of whether those coping strategies that had the highest correlation with burden were also those strategies that were most frequently used by caregivers. For this analysis, the scores for each F-COPES coping strategy were calculated based on the sum of the ratings for individual items representing that strategy. To facilitate comparison of the relative use of each coping strategy, the summed raw scores were divided by the number of items used to assess that strategy. Using this procedure, it was possible to rank order the coping strategies in terms of how frequently they were used by caregivers. These data are presented in Table 3.

Table 3.
Caregiver's Ratings of F-COPES Coping Strategies

Coping Strategy	Mean	SD	# Items	Comparison Mean
Internal Strategies				
Conf. in prob. solving	15.72	2.87	4	3.93
Reframing	15.69	2.39	4	3.92
Passivity	7.62	2.96	4	1.91
External Strategies				
Spiritual support	14.60	4.43	4	3.65
Friends	14.32	3.04	4	3.58
Community resources	10.63	2.78	3	3.54
Extended family	13.48	3.47	4	3.37
Neighbors	8.03	3.11	3	2.68

Note: Rating scale: 1 = Strongly disagree that this coping strategy is used, to 5 = Stronly agree that this coping strategy is used.

Of the three coping strategies that were related to burden, only confidence in problem solving and use of spiritual supports were frequently used by caregivers. The third strategy which was related to burden, use of neighbors, was one of the two least frequently used strategies (passivity being the least used). Among the internal coping strategies, confidence in problem solving was the highest rated (comparison mean = 3.93), followed by reframing (3.92) and passivity (1.91). For external coping strategies, use of spiritual support was rated highest (comparison mean = 3.65), followed by use of friends (3.58), community resources (3.54), extended family (3.37), and lastly, use of neighbors (2.68).

Discussion

Burden

The level of burden reported in the present analysis is lower than that reported in other studies of caregiving (Pratt, et al., 1985; Zarit, 1982), but this is understandable given the fact that other studies have focused in particular on caregiving situations where the person receiving care is significantly impaired in terms of functional ability (e.g. Alzheimer's). The older parents receiving care and support in the present study appear to have been healthier and to have higher functional capacities on the average than those in other caregiving studies.

The finding that female caregivers (daughters) reported higher levels of burden than did males, however, confirms a

repeated observation in caregiving research. This finding, coupled with the fact that the number of dependent children under the age of 18 residing in the caregiver's home, identifies what might be an "at risk" population with regard to caregiving: middle-aged women who have not yet experienced the launching of children and who are "squeezed" between the responsibilities of caring for children and parents/in-laws.

It is important to note that while the data in this preliminary study suggest that certain individuals are at greater risk of subjective burden than others, the restricted characteristics of the respondents necessitates caution in making generalizations about the characteristics of caregivers who are at high risk. The caregivers in the current study were for the most part middle- and upper-middle class, caucasian adult children assisting elderly who, for the most part, were not significantly impaired in terms of either mental or physical functioning. A more representative sample of caregivers and non-caregivers must be studied to more accurately identify high-risk groups.

Coping Strategies

One of the most surprising findings in the study was that burden was not related to coping stragegies involving the use of extended family and friends as a sources of support in caregiving. Other researchers have reported that immediate families are generally the primary source of support for long-term, chronic disability. Gottlieb (1983), for example, maintains that the family is of paramount importance in the emotional

life of a caregiver, rendering criticial psychosocial resources, particularly in the face of inalterable stress. Typically, the caregiving responsibilities fall on the shoulders of spouses (wives) and one or more adult daughters. In this process, the caregiver may often receive needed affective support from extended family. And according to the "principle of substitution" (Johnson, 1983), friends fill in when members of the extended family are unable or unwilling to assist in caregiving. In the present study, not only were coping strategies involving the use of extended family and friends not correlated with feelings of burden (and hence not considered significant mediators of burden), the frequency with which respondents reported using strategies involving these sources of support was also relatively low when compared to other coping strategies. The use of friends as a source of support in caregiving was used about as much as were community resources, but even here this was more true for female than male caregivers.

Even in the face of these findings, the fact that use of family as a source of support was not significantly related to burden needs to be interpreted cautiously. It may be the result of the particular nature of the caregivers included in the study. It might be, too, that while extended family assistance was not related to feelings of subjective burden, family support might be an important mediator of more objective measures of burden (Montgomery, et al., 1985).

Finally, some comments need to be made about the use of

spiritual support as a coping strategy. Not only was spiritual support the most frequently used external coping strategy, it was also likely to be used by respondents almost as frequently as the internal strategies of confidence in problem solving and reframing. In fact, the strategy of spiritual support might in many ways be related to the strategy of reframing. For example, spiritual support may serve as the basis for controlling the meaning of difficulties faced during the experience of caregiving. Spiritual support may provide the caregiver with a perspective that allows him/her to discern some of the positive attributes of the situation, or in making positive comparisons to others who might be facing even more difficult situations.

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THE ALZHEIMER SPOUSE: CARING AND COPING

By

Marjorie P. Westergard

The thoughts and observations in my paper are the result of my own experiences as an Alzheimer's spouse for the past eight years, and experiences of members of our support group.

Alzheimer's Disease is a terminal brain disease which affects memory and personality. It usually attacks adults over the age of forty, and is the fourth major cause of death in people over the age of 65. At the present time there is no treatment or cure.

Six years ago, when my husband was diagnosed, most of the general public was unfamiliar with the word "Alzheimer"; however, in a recent survey, when participants were asked to name the disease they feared most, Alzheimer's placed second, only behind cancer.

Most AD patients live at home until late in the illness, placing the stressful and demanding burden of care upon family members. Many families complain that physicians often do not adequately inform them about the disease, its stages, or offer any means of support. This results in frustration and feelings that no one cares or understands. Often family members who do not spend as much time with the victim may be unsympathetic and unconvinced that there really is a problem.

The caregiver of an AD victim must have a thorough understanding of the disease and must realize that the patient is not responsible for his words or actions. Because AD victims often seem uncooperative, or even mean, they are highly susceptible to physical and mental "abuse" in nursing homes and in their own homes.

The following suggestions can be helpful to caregivers. Be patient and calm, allowing plenty of time to communicate with him. Speak slowly and simply, presenting only one idea at a time. Keep activities simple. (A confused person becomes easily frustrated when faced with multiple-step tasks.) Don't ask questions that tax his memory. Give him answers, instead. Do not assume that he can understand and act on messages, either written or verbal. These expectations are unrealistic. Use the same safety precautions used for children. Avoid situations which bring about frustration and anger. Do not accuse the patient of lying, and don't be upset if he makes unkind remarks about you, or is not tactful in public. Above all, love him, show affection, give him the respect he deserves.

The loss of the abilities to think, remember events, and make rational judgments create perplexing behavior patterns which are very difficult for care-

givers to deal with.

Friends often decrease their social visits as the patient's behavioral problems worsen. Many spouses stop taking patients out in public because of possible embarrassing acts. Since AD often causes inappropriate behavior, it is helpful to explain the disease and the behavior to friends and neighbors.

The AD patient forgets what has been done or said from one minute to the next, and a common source of frustration for the caregiver is the repetitive questions and demands made over and over. Sometimes a distraction, giving him a simple task, will take his mind off the matter for awhile.

When the AD victim appears stubborn and uncooperative, don't take his comments personally or try to reason or contradict him. Try to accept the fact that he is not responsible.

The AD patient may put things down, or even hide them, and forget where. It is a good idea to inspect waste baskets, drawers, shoes, under cushions and favorite hiding places. Keep spare sets of keys, glasses, hearing aid batteries, etc.

Wandering, so common with AD victims, is a problem which requires either constant supervision or a secure environment. An ID bracelet, engraved with "memory impaired", name, address, and phone is essential for the wanderer.

A patient may retain his driving skills, but his loss of judgment makes him a hazard on the highways. Taking away his keys presents a major challenge for the caregiver. It is at this point that a "white lie" is often better than trying to explain why it is no longer safe for him to drive. Some families have disconnected the battery or starter wire and told the impaired person that the car couldn't be fixed. Caregivers have to learn to be creative in problem-solving attempts, and what works one day will not always work the next.

It is common for an AD victim to refuse to bathe or shower. Avoid discussing whether or not the bath is needed or reminding him it has been three days since he last bathed. Instead, look for ways to simplify the number of decisions involved in the process of bathing and dressing. Follow the same routine every day. Don't argue when the patient says no, just calmly continue helping him, step by step. A temporary change of subject will often cause the person to forget his objection.

Because an AD victim is no longer able to evaluate the consequences of his actions, accidents can easily happen. Since he is unable to learn, special care must be taken to guard against accidents. The same safety precautions for children

apply to the Alzheimer victim.

If friends and family assist, the patient can often remain at home until the later stages of the disease. "Baby-sitters" must understand the nature of the disease and not be insulted by offensive behavior. Help them feel comfortable around your loved one.

Alzheimer Family Centers are beginning to emerge across the country, offering day-care to the afflicted person at very reasonable rates. These are usually run by individuals or civic groups. The Dept. of Aging in Utah has started a Senior Companion Program that can provide some respite care for AD spouses. More and more nursing homes are offering day-care, but they are still quite expensive. Day-care centers are the last stop before nursing homes.

When is nursing home placement necessary? When the caregiver can no longer physically or mentally handle the situation. Since most AD victims are senior citizens, the burden is often too great for the caregiver, who may also be aged. Statistics show that spouses are dying before the victims.

Unfortunately, there is still a stigma against those who find it necessary to place a loved one in a nursing home. When we had to place my husband in a care center two and a half years ago, several well-meaning friends criticized my decision. This did not help the guilt I already felt. Harold's doctor suggested that the next time a comment was made, I should look back and see how many times that individual had offered assistance during my time of need. AD patients are often troublesome and uncooperative in nursing home situations and, therefore, are not always popular among the patients or the staff. It is imperative that the staff understands dementing illness and how to care for people suffering from it. Regular in-service training should be maintained. My dear husband was abused in a care center by an orderly who definitely did not understand AD. The orderly had attempted to use a behavioral contract on Harold, and, in my presence, shook and scolded him for not keeping his part of the agreement, which was to cooperate when it was time to change his clothes. When I reminded him that my husband suffered from AD and could not remember a promise, he looked at me and replied, "He remembers you, doesn't he?" I didn't sleep for two nights, wondering how that orderly treated my husband when I wasn't there. The administrator called me a few days later and apologized, stating that the orderly had been dismissed. But I was relieved when we found a care center where I felt the entire staff, including the cleaning people, loved and cared for my husband. A nursing home should also provide a safe place for AD patients to do their wandering, so that physical restraints can be kept at a minimum. If you visit a care center during

the day, unannounced, you can usually "feel" the atmosphere as you observe the relationship between staff members and patients. AD patients don't require as much skilled care as they do patient and loving concern from a nurse or an aide.

There is much diversity in the way families cope with AD. Some families suffer irreparable damage as anger, guilt, resentment and refusal to accept the illness tear the family apart. Other families find the illness brings them closer together in their efforts to assist the ill loved one and give each other support. It is important to realize that it is understandable to feel frustrated, sad, and angry with what is happening, but those who are willing to accept the fact that things will never again be the "way they were" can proceed to build a quality "new life."

One of the most challenging new roles for a spouse is that of total caregiver. A spouse must take on responsibilities that were formerly carried on by the victim. In most cases, the spouse lacks the preparation for assuming the role of his mate. When AD strikes younger adults, the spouse unwillingly becomes the breadwinner and caregiver.

AD does not have to mean an end to enjoying life. It does mean that you will need to make a special effort to find things that give pleasure to the impaired person, constantly adjusting to the stage that he is in. Although early in the disease, we had to stop attending the symphony and opera, I was able to take Harold to movies for some time, as long as we arrived in time to sit on the back row, with Harold in the corner. He was able to sit and stand at will, unobserved by the majority of theater patrons. We were also very selective in our seating at restaurants, and usually could conceal Harold's problem, although explanations to the waiter were often necessary. I learned to be very creative in planning recreational activities.

Because AD affects the brain, which is not visible, the patient often looks physically healthy. This creates the problem of having others, including family, realize that the person is ill and may need special attention and supervision. Persons not knowing the situation may feel that the caregiver is "over-protecting" or not treating the patient properly. The caregiver then feels frustrated and angry when others do not recognize the seriousness of the problem or do not lend the support so desperately needed by both patient and caregiver.

I remember a discussion with a leader in my church. I had mentioned how exhausting it was to work six days a week, trying to salvage a business that my

husband had almost ruined. (I took Harold to work with me, and tried to care for him there.) My friend said he knew exactly how I felt, because he, too, worked long hours and then spent Sundays in meetings all day. He didn't understand my problem at all. When he went home at night, he had a wife and dinner waiting for him. When I went home at night, after working 10 to 12 hours as breadwinner, I had to assume the role of homemaker and was often too tired to get all my tasks done, which added to my frustration.

Families and friends need to be educated. Family members who do not spend time with a victim may be unsympathetic and unconvinced there really is something wrong. If you are getting criticism or not enough help from your family, don't allow your resentment to smolder. It may be up to you to take the initiative to change things in your family. You may need to provide them with a first-hand learning experience. A lady in our support group was visited by a son and his family, from out of state, for a few hours last Thanksgiving. The son commented to other family members that he didn't know why mother was so upset. Dad seemed perfectly normal to him. During the Christmas holidays this lady, with her afflicted husband, spent two weeks with this son in Texas. The son now feels Dad should be placed in a nursing home immediately.

I recently talked with a young man whose mother, a prominent civic and church leader, is a victim of AD. I told him that our family had received many blessings since this tragedy struck. He asked me to name one good thing resulting from Harold's illness. I told him we had learned patience. All of our children have developed a greater sensitivity to the needs of relatives, friends, and neighbors, who face similar problems. After reflecting on my words for a moment, the young man replied, "You're right. My father, a successful businessman, was always too busy to get involved in family concerns. The family always catered to his wishes and schedules. Now he is developing traits of kindness and patience, that were never manifest before."

Dr. Peter Rabins, in the book "The 36-Hour Day" states: "Laughter might be called a gift to help our sanity in the face of trouble."

A year after Harold was diagnosed, he returned to the U.of U.Medical Center to repeat the tests. He was to spend four days there, as he had the year before. But on the morning of the second day, I received a call urging me to come immediately. Harold had become very violent and had "stolen" items from every nurse's station on the floor. (The nurses could not understand how he managed to get his hands on so many items without being detected. I didn't dare tell them that, among his

many talents, Harold had been an amateur magician and was very good at "slight of hand.") As we emptied his suitcase of pens, pencils, note pads, hypodermic needles, syringes, bottles, even a pack of cigarettes, Harold entered the room, grabbed the suitcase and locked himself in the bathroom. All chaos broke out. Orderlies were knocking on the door, urging Harold to let them in. Harold was yelling to leave him alone. Finally, a security guard forced the door open. We were literally pushed out of the hospital, with Harold still shaking his fists and yelling, and with the orderlies begging him not to return. Later that evening, as I tearfully related this humiliating experience to my daughter, she started to laugh, saying, "Mother, your description of the incident is really funny." We both started to laugh and cry at the same time, and it was at that moment that I learned to substitute laughter for tears whenever possible. I felt much better.

There is no reason to feel ashamed if you laugh about the mistakes a confused person makes. He may share the laughter even if he is not sure what is funny. One evening all of our family, including spouses, loaded in our van to make our annual trip to the Barbershop Concert in Salt Lake. From the moment the key went into the ignition, Harold began bombarding me with questions. "Where are we going? What time does it start? What time is it now? Where is it going to be held? What time will we get there? What time will we get home?" Over and over again. Finally, I assigned each person a question to answer, and I concentrated on driving. Answers were coming from all directions, and everyone, including Harold, was laughing.

During a particular dark period in my ordeal, I heard that a good friend had commented on how "bad" I was beginning to look. I didn't want to look "bad". I decided I could still look "good" in spite of my worries and concerns. I determined to always look my best and to try to maintain a cheerful attitude. It wasn't always easy, but I felt better for pursuing this goal.

Caregivers need to be nourished, too, and sometimes it may be necessary to develop your own support system. Metropolitan opera star, Dorothy Kirsten, whose husband, former director of the Brain Institute at U.C.L.A., is suffering from AD, commented that she had seen friends, many of whom she thought were of the lifetime variety, and "certainly were with us when I was playing the prima dona," simply drop out of sight. No calls, no notes, not even a brief "thinking of you" message. So she has organized a national campaign to publicize AD and to raise funds for research. This has been her outlet. Caregivers need to find time to recreate, have fun, laugh, even if for only a few minutes each day.

When friends ask what they can do to help, be specific and commit them right on the spot. I had suggested to many of our friends that taking Harold for a ride sometime would be very helpful. In four and a half years, only two of them responded. I should have named the hour and the day I needed this service.

It is quite common for family members to feel guilty for the way they treated the patient in the past; for being embarrassed by the person's inappropriate behavior; for losing their temper; for not wanting this responsibility; and for considering a nursing home. I'll never forget the hurt look on Harold's face when I slapped him because he refused to get in the shower after an accident, and my son wasn't home to help me. Fortunately, he can't remember the incident, but I do. Caregivers need to discuss their feelings and frustrations with others with similar problems. One caregiver remarked, "We have some fights, but with AD patients, you don't make up, you just erase it and start again." Some of us have to "start over" many times.

Financial worries are a major concern for most caregivers. Costs of caring for the patient at home or in a care center can be extensive. The victim may be terminated from a job, or the spouse may be required to resign early in order to care for the victim. Home-care expenses, adult day care, nursing services can deplete a family's financial resources. In our case, my poor husband had made so many judgment errors before we realized he was sick that we lost all of our savings, health and life insurances, and almost lost our business. It's not easy to ask for help, financially, but it usually becomes necessary. All avenues of financial assistance, including social security, veterans, and church should be explored. When I was forced to sell Harold's very valuable stamp and coin collections and other beloved treasures that he had planned to leave to our children, it would have been very easy to endulge in a little self-pity. Instead, I looked at this as an opportunity for Harold to still contribute to the support of his family. It was much easier that way.

I have also learned to accept financial contributions from friends and family graciously. Recently a beautiful Korean family presented me with a check for $100 to help the "bishop" who had assisted them upon their arrival in Utah. Realizing what a sacrifice it must have been for them, I accepted it with much gratitude.

It is essential that you caregivers have others to help - to give you "time-out" from constant care; to give you encouragement and support; to help with the work, and to share the financial responsibility.

At the present time Alzheimer support groups are meeting regularly in several Utah cities. Support groups have been the greatest source of strength for me, as experts from all fields offer advice, and as we share our concerns and exchange information with others facing the same problems.

A few years ago Mark Payne, from BYU, conducted a survey on support groups in the state. One interesting conclusion from the report was that although those who attended support meetings didn't actually know any more about AD than those who did not attend, the support group members thought they did, so were better able to cope with their situations.

During these past several years, I have read and studied many books on overcoming personal tragedy; I have listened to speakers who have emerged on top of great sorrows and trials; and I have tried to place myself in as many happy, beautiful surroundings as possible. I have made myself remember the good things in my life, and I have tried to uplift others.

There was a saying during World War II that "there's no such thing as an atheist in a fox hole." I think I could say, "There's no such thing as an atheist Alzheimer spouse." During the past eight years I have learned to pray, and I have found a "best friend" who never leaves my side.

In our support groups many report that they have received help and encouragement from their local churches, while church support has been sadly lacking for others. In some areas church groups have organized special "teams" who regularly take turns offering respite care to the caregiver. More churches are expressing interest in learning how to assist their members who are afflicted with this disease. Our support groups offer educational programs to church and civic groups to help them gain a better awareness and understanding of the needs of both the AD victim and the caregiver.

My family and I have grown, and are continuing to grow, from the experiences we have had with an Alzheimer victim. I like to think that, in his way, Harold is still guiding his family, by providing us with experiences and opportunities, and that, perhaps, if he had been given the choice, he would have eagerly made this sacrifice to help us become better individuals.

Caregivers of AD victims are facing a tremendous challenge today. Alone, they cannot possibly handle the burden and stress piled upon them, but with the help and support of family, friends, and support groups, they can still maintain a meaningful life, with a brighter future ahead.

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In our support groups many report that they have received help and encouragement from their local churches, while church support has been sadly lacking for others. In some areas church groups have organized special "teams" who regularly take turns offering respite care to the caregiver. More churches are expressing interest in learning how to assist their members who are afflicted with this disease. Our support groups offer educational programs to church and civic groups to help them gain a better awareness and understanding of the needs of both the AD victim and the caregiver.

My family and I have grown, and are continuing to grow, from the experiences we have had with an Alzheimer victim. I like to think that, in his way, Harold is still guiding his family, by providing us with experiences and opportunities, and that, perhaps, if he had been given the choice, he would have eagerly made this sacrifice to help us become better individuals.

Caregivers of AD victims are facing a tremendous challenge today. Alone, they cannot possibly handle the burden and stress piled upon them, but with the help and support of family, friends, and support groups, they can still maintain a meaningful life, with a brighter future ahead.